Daily physical activity in patients with a chronic disease

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Introduction

Physical inactivity is one of the foremost risk factors of death caused by chronic diseases.[1] The World Health Organization estimates that approximately 3.2 million deaths are a result of physical inactivity each year.[1] Even though physical activity is currently being increasingly recognized as an important strategy for disease prevention and disease management,[2, 3] it does not automatically correspond to all patients being regularly physically active.[4-9] Physical inactivity is believed to be common in many patients, but it is unclear how much physical activity patients actually perform, which patients are meeting physical activity guidelines, and which factors are related to physical activity.

Therefore, the aim of this thesis is to contribute to the scientific knowledge regarding the physical activity behaviour of patients with a chronic disease. This information can be useful in the extensive process of optimizing physical activity guidelines and interventions in the attempt to increase physical activity in inactive patients.

Chronic diseases

Chronic diseases are diseases of extended duration and generally slow progression. They can have multiple complex causes and risk factors such as smoking, being overweight, and physical inactivity.[10, 11] An extended course of illness and physical or functional disability is characteristic for these types of diseases.[10, 11] Diabetes, cardiovascular disease, cancer, arthritis, and depression are a few examples of worldwide highly prevalent chronic diseases.[1, 10-13] The prevalence of chronic diseases is increasing and, due to improved medical care prolonging life, additional diseases will eventually become chronic diseases. Chronic diseases are the major causes of death among the worldwide adult population, and the number of chronic disease related deaths is expected to increase by 15% within the forthcoming decade.[1] The World Health Organization demonstrated that the (financial) burden of chronic diseases such as heart disease, diabetes, asthma, cancer, depression and arthritis is high, and it is expected to increase in the upcoming years due to the aging population.[1, 12]

The importance of physical activity

Chronic diseases are often related to diminished physical capacity and functioning which subsequently lead to an increased risk for an inactive lifestyle in patients.[14-16] The relationship is reciprocal as research has substantiated that a physically inactive lifestyle contributes to a decreased physical capacity and functioning as well.[17, 18] This vicious circle of deconditioning and related physical inactivity increases the vulnerability of patients for, in addition to the disease related issues, further health problems such as obesity, high blood pressure and other chronic diseases including diabetes mellitus or cardiovascular diseases.[2, 19] To decrease the burden of disease and the accompanying healthcare expenditures, strategies for preventing and managing chronic diseases are urgently needed, and there are several reasons why physical activity is an important factor in such a strategy.[1, 19, 20] First, regular physical activity can prevent the development of many chronic diseases such as cardiovascular disease,[2, 21] diabetes,[2, 22] asthma,[23] breast cancer,[2, 24] and depression;[25, 26] second, for patients already experiencing a chronic disease, regular physical activity can decrease the progression or complications of the disease;[2, 19] and third, regular physical activity can improve the psychosocial well-being and quality of life in patients with a chronic disease.[19, 27-29]

Definition of physical activity

In order to interpret the relationship between physical activity and health, it is important to clarify what is exactly meant by the term physical activity. Often, the terms physical activity and exercise are used interchangeably or are confused with each other. In 1985, Caspersen et al., defined *physical activity* as "any bodily movement produced by skeletal muscles that results in energy expenditure". [30] Physical activity in daily life encapsulates all physical activities during the day, e.g., occupational, household, and leisure time physical activities. Walking, cycling, and gardening are typical examples of leisure time physical activities but exercise can also be included. *Exercise* is defined as "a subset of physical activity that is planned, structured, and repetitive and has, as a final or an intermediate objective, the improvement or maintenance of physical fitness".[30]

Exercise

Traditionally, the focus in physical activity research, interventions, rehabilitation programs, and recommendations is on exercise.[19, 31] The beneficial effects of exercise are well-known, and exercise is often used for prevention or treatment of various diseases.[19] However, although exercise programs are successful for improving physical fitness, physical activity, and health,[32-35] after an exercise program has been completed, compliance to the exercise recommendation is low.[36-38] Consequently, many people do not perform regular exercise.[39, 40] People may encounter many barriers to exercise such as a lack of time, being averse to exercise, physical or financial limitations to visit a sport center, etc.[40, 41] Patients with a chronic disease may encounter additional barriers to exercise such as physical or psychological limitations as a consequence of their disease.[42-45] Although research indicates that patients should be encouraged to exercise,[19] it is unknown whether patients are actually willing to participate in exercise programs.

Daily physical activity

Beginning in the early 1990s, the paradigm of *exercise* versus *physical fitness* has changed into *physical activity* versus *health*. [46] It became evident that, in order to maintain or improve health, it is not necessary, per sé, to perform exercise. By performing daily physical activities, also referred to as habitual physical activity or lifestyle physical activity, it is possible to benefit from the health effects of physical activity as well. Research by Westerterp (2001) indicates that the duration and intensity of physical activity are interchangeable with regard to energy expenditure.[47] When performing light-intensity physical activity for a longer period of time the energy expenditure is equivalent to the energy expenditure of performing vigorous-intensity physical activity for a short period of time (Figure 1). Not everyone is capable of performing exercise, especially older adults and patients suffering from a chronic disease; [47] however, everyone can perform some form and level of daily physical activities even when there are certain limitations in performing activities due to age-related or disease specific characteristics. Daily physical activities are generally at a lower intensity compared to exercise and can, therefore, be performed for a longer period of time. Furthermore, lifestyle activities do not necessitate paying money and can be easily integrated into daily life. Because it becomes a part of a daily routine, daily physical activity is possibly easier to sustain long term than exercise.

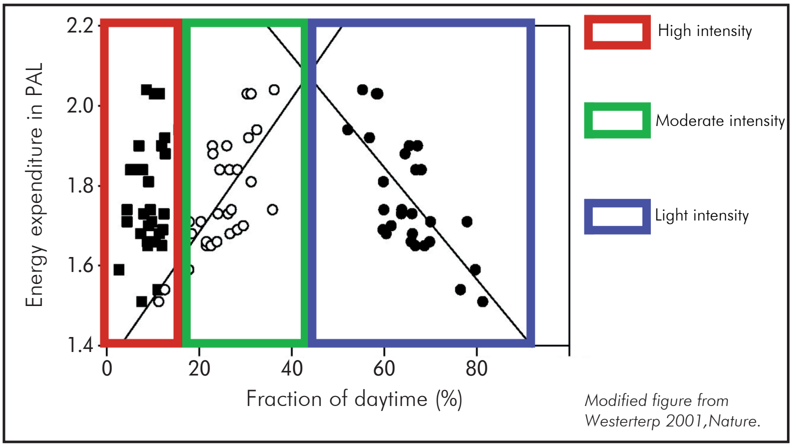

Figure 1 Intensity and duration of physical activity are interchangeable

An increasing number of studies demonstrated that activities with low to moderate intensity (typically daily physical activities) have beneficial effects on health.[48-56] For example, daily physical activity is associated with improved glucose metabolism [48, 49] and decreased blood pressure.[48, 50, 51, 55] Moreau et al. (2001) showed that, after 24 weeks of daily meeting the ACSM recommendation by walking activities, the blood pressure of middle-aged women decreased comparably to traditional exercise programs.[50] Another study indicated that daily physical activity is not only as effective as exercise in decreasing blood pressure but also in increasing physical fitness.[51] They compared the effects of a structured exercise intervention, which consisted of 3-5 supervised training sessions at 50-85% of maximum aerobic power for 20-60 minutes, with a lifestyle intervention in which participants were encouraged to accumulate at least 30 minutes of moderate-intensity physical activity on most days of the week. After 24 months, both groups had a significant and comparable improvement in cardiorespiratory fitness as illustrated by an increase in VO^2max.[51]

Daily physical activity is also inversely related to body weight and fat percentage.[52, 53] In one study with a sample of 109 healthy adults with a mean age of 44.9 (SD 15.8) years, participants who took more than 9000 steps per day more often had more often a healthy BMI (<25).[53] In contrast, the BMI of participants who took less than 5000 steps per day was more often in the obese category (BMI≥30). Colpani et al. (2012) found that women between 40 and 75 years of age who walked at least 6,000 steps per day had a lower BMI, less central adiposity, and lower prevalence of diabetes, metabolic syndrome and cardiovascular diseases, than women who walked less than 6,000 steps per day.[52]

In summary, traditionally, the focus in physical activity research was primarily on exercise, but more recent insights reveal that attention should be paid to daily physical activity as well. Not every patient is capable of performing exercise, and compliance is generally low. Performing daily physical activities can induce beneficial health effects as well, which will endure over a prolonged period of time. However, how much physical activity is required to attain beneficial health effects? To date, to maintain or improve health, adults (50-64 years) with clinically significant chronic conditions are recommended to adhere to the recommendations for healthy adults as much as their abilities and conditions allow.[31, 57] This indicates that patients with a chronic disease should attempt to accumulate 30 minutes of MPVA at least five days per week [31, 57] or should attempt to take an average of 10,000 steps per day.[58] Research suggests that the majority of patients with a chronic disease are not meeting these recommendations. [4, 6-9] However, this is primarily based on subjective physical activity measurements which are known to have validity and reliability issues.[59-62] The measurement error of subjective measurements can be large, because responses to questionnaires are influenced by perception, cultural factors, social desirability, and the memory of the respondent.[59] Yet, although the utilization of questionnaires for measuring physical activity have certain disadvantages, due to the significant advantages, they continue to be used often. Questionnaires are easy to administer, not expensive, they are applicable on a large scale, and can be employed to classify respondents into active versus inactive subjects. However, for more accurate and detailed information regarding physical activity during the day and compliance with guidelines, physical activity should be monitored with more objective measurement methods such as accelerometry.[63, 64] It is unknown whether physically inactive patients were already inactive prior to being diagnosed with a chronic disease or whether they decreased their level of physical activity after being diagnosed. Some studies suggest that patients continue to be inactive or even become less physically active after being diagnosed with a chronic disease [65-68] possibly as a result of the physical or psychological limitations of their disease. In contrast, other studies suggest that patients become more physically active after being diagnosed with a chronic disease[69, 70] because they may experience their diagnosis as a 'wake-up call' for adopting a more healthy lifestyle. To date, it remains uncertain whether physical activity increases or decreases after being diagnosed with a chronic disease or how physical activity develops over time.

Aim and outline of this thesis

Due to the convincing evidence of the benefits of physical activity, a prescription of physical activity for patients with a chronic disease should become routine clinical practice. It is initially important to have increased insight into the current physical activity behaviour of patients with a chronic disease, therefore, the **overall aim of this thesis** is to acquire more knowledge about daily physical activity in patients with a chronic disease: How physically active are patients? Which factors are related to physical activity in patients with a chronic disease?

To date, there is still only limited knowledge about physical activity in patients with a chronic disease. We know that exercise can have beneficial effects for many patients; however, not all patients are motivated or capable of performing exercise. **Chapter 2** describes the willingness of adult patients with congenital heart disease (GUCH) to participate in an exercise program and factors that affect their willingness to participate. The importance of exercise for GUCH patients has only recently been recognized. Whereas, formerly, many children with congenital heart disease did not survive to adulthood, due to improved medical care and diagnostic capabilities, the majority now survives to adulthood. The focus of medical care is shifting from survival to the quality of life and wellbeing in which exercise is an important factor.

However, research showed that the compliance to exercise is low, especially when the structured intervention or program has been completed. Because daily physical activity has beneficial health effects as well, it is easier to integrate into daily life and can be performed by anyone (including patients with a chronic disease), at least to a certain extent, the attention of exercise scientists has now shifted from exercise and physical fitness towards physical activity and health. Therefore, **Chapters 3 - 6** of this thesis are focused on daily physical activity in patients with a chronic disease.

After being diagnosed with a chronic disease, patients' physical activity level can decrease due to physical or psychological limitations of the disease. In contrast, newly diagnosed patients can experience their diagnosis as a warning to adopt a more healthy lifestyle. To date, it is unknown whether patients will increase or decrease their daily physical activity after being diagnosed with a chronic disease. **Chapter 3** describes how physical activity in middle-aged women is longitudinally affected by the diagnosis of a chronic disease including heart disease, diabetes, asthma, breast cancer, arthritis, and depression.

Research suggests that physical activity levels in chronically ill patients are often low and many patients do not meet the recommended levels of physical activity; however, due to methodological issues, it remains unclear to what extent chronically ill patients (are able to) comply to the physical activity guidelines. [5, 6, 8, 71-75] There can be a large variability in daily physical activity between and within patient groups. [71] **Chapters 4, 5,** and **6** focus on describing daily physical activity of patients with respectively heart failure, Parkinson's disease, and renal transplantation as measured by accelerometry. By using accelerometry it is feasible to examine compliance to the physical activity guidelines and show the variability in daily physical activity between patients.

Different determinants can play a role in daily physical activity. [76] However, it remains unclear which factors -and to what extent- influence the variability in daily physical activity in patients with a chronic disease. **Chapters 4** and **5** describe which factors are associated with daily physical activity in patients with heart failure and Parkinson's disease, respectively.

In the exceptional case of a cured disease, (part of) the limitations for performing physical activities are no longer tenable. For example, former patients with chronic kidney disease have, in theory, no restrictions for performing activities after receiving a healthy donor kidney. However, it is unknown whether patients increase their physical activity spontaneously after being cured. Therefore, in **Chapter 6**, the changes in daily physical activity in renal transplant recipients in the first year following transplantation are examined.

Finally, **Chapter 7** comprises the general discussion of the primary findings of the previous chapters, methodological considerations, and recommendations for future research.

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2

Are grown-ups with congenital heart disease willing to participate in an exercise program?

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Abstract

Objective

To examine the willingness of grown-ups with congenital heart disease (GUCH) to participate in the GUCH Training Program-Individualised (GTI), an exercise program specifically designed for GUCH, and to identify factors affecting their willingness to participate.

Design and setting

In this cross-sectional study, all outpatient GUCH of the University Medical Center Groningen in the Netherlands, living within a 30-km radius of Groningen (n=311), were asked to participate.

Patients

In total, 116 (37%) of the 311 GUCH who are invited to participate in our study returned completed questionnaires. The median age of the respondents was 40 (interquartile range 31-50) years and 55% were women.

Outcome measures

Respondents (n=116) completed a questionnaire that queried physical activity, perceived physical fitness, psychosocial determinants (motivation, self-efficacy, and social support) related to physical activity, and willingness to participate in GTI.

Results

Of the 116 respondents, 68 (59%) were willing to participate in GTI. They were less physically active, had worse perceived physical fitness, were less satisfied with their fitness, were generally more motivated to engage in physical activity, and had more social support than patients unwilling to participate. The best logistic regression model predicting willingness to participate in GTI included the variables perceived physical fitness and motivation for physical activity in general.

Conclusions

Asking GUCH to participate in an exercise program supervised by physical therapists is a good strategy. Taken into account nonresponse, a participation rate in the exercise program of over 20% is to be expected. Perceived physical fitness and motivation for physical activity in general are important predictors of patients' willingness to participate.

Keywords

Exercise; Congenital Heart Disease; Physical Activity; Perceived Fitness; Motivation

Introduction

The population of grown-ups with congenital heart disease (GUCH) continues to grow.[1, 2] Nowadays, the focus of cardiac medical care has shifted from survival to terms of quality of life.[3-5]

Exercise capacity is central to quality of life but is often reduced in GUCH.[6-9] Reduced exercise capacity can be caused by not only cardiopulmonary problems,[8] overprotection, or fear,[10-12] but also by a sedentary lifestyle.[8,13,14] Hence, GUCH should be encouraged to be physically active, including exercise training and sports,[2, 8,15] because doing so can improve their exercise capacity,[6, 8, 16] Furthermore, enhanced physical activity can improve self-esteem and can positively affect cardiovascular, musculoskeletal, and functional status. Together, this will result in an improved quality of life.[15] Physical activity and exercise training is safe for the majority of cardiac pathologies in GUCH.[6,14,17]

An exercise program called the GUCH Training program- Individualised (GTI) has been developed to increase exercise capacity, with the aim of improving quality of life. Although previous research suggests that most GUCH are interested in exercise and appropriate advice,[10, 18] it is unknown whether GUCH are willing to participate in exercise programs. Multiple factors might contribute to their 'willingness', which is defined as the actual commitment to participate in GTI. For example, demographic, clinical, or psychosocial factors, current physical activity level, or perceived physical fitness may play a role.

The objective of this study was to examine the willingness of GUCH to participate in an individualised exercise program (GTI) intended to improve their exercise capacity. The second objective was to identify factors that predict their willingness. The effects of GTI will be evaluated in a future study.

Methods

Study Sample and Design

In this cross-sectional study, all outpatient GUCH of the University Medical Centre Groningen in the Netherlands, living within a 30-km radius of Groningen (n=311), were asked to participate. The study complied with principles outlined in the Declaration of Helsinki and was approved by the local ethics committee. All participants gave their informed consent.

Data Collection

All 311 patients received a physical activity questionnaire (Godin Leisure Time Questionnaire)[19] and a short questionnaire we developed – partly based on the Theory of Planned Behaviour –

to gather information on demographic characteristics, perceived physical fitness, psychosocial determinants related to physical activity (motivation, self-efficacy, and positive and negative social support), and willingness to participate in an exercise program. Respondents not willing to participate in GTI were labelled 'GTI-no'; those willing to participate were labelled 'GTI-yes'. Disease-specific characteristics were derived from respondents' medical records.

Data Analyses

Descriptive statistics were used to examine respondents' characteristics and willingness to participate in GTI. Mann-Whitney U-tests (two sided) and chi-square tests (two sided) were conducted to examine differences between 'GTI-yes' and 'GTI-no'. Logistic regression analyses (method backward: likelihood ratio [LR]) were used to identify variables that predicted willingness to participate in GTI. All analyses were performed with SPSS (SPSS Statistics for Windows, Version 17.0, Chicago, IL, USA); $P < .05$ was considered statistically significant.

Results

Study Sample

In total, 116 (37%) of the 311 GUCH who are invited to participate in our study returned completed questionnaires. Characteristics of the study sample are presented in Table 1.

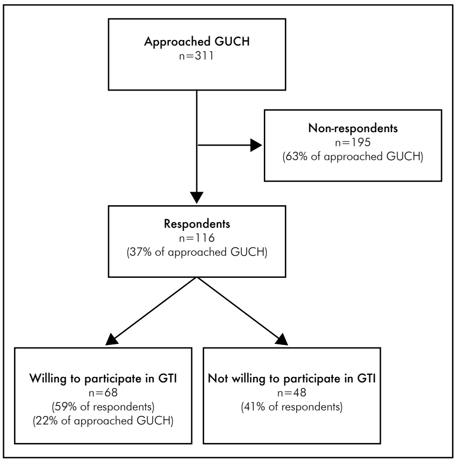

Figure 1 Flowchart: visual presentation of the response rate and the number of patients willing and not willing to participate in GTI. GTI, GUCH Training Program-Individualised; GUCH, grown-ups with congenital heart disease.

Table 1 Study Sample Characteristics of All Respondents (n = 116), GTI-yes (n = 68), GTI-no (n = 48), and Differences between the Groups

Demographic Characteristics	Total (n = 116)	GTI-yes (n = 68)	GTI-no (n = 48)	χ^2/ *U*	*P*
Age (years)	40 (IQR 31-50)	40 (IQR 29-53)	41 (IQR 34-48)	1590.5	.816
Gender					
Men	52 (45%)	29 (43%)	23 (48%)	.316	.705
Women	64 (55%)	39 (57%)	25 (52%)		
BMI	25.1 (IQR 22.8-27.5)	25.5 (IQR 23.3-28.1)	24.7 (IQR 22.1-26.3)		
Overweight (BMI 25-30	38 (37%)	27 (42%)	11 (30%)	993.5	.118
Obesity (BMI >30)	14 (14%)	11 (17%)	3 (8%)		
Level of education					
Low-Moderate	73 (64.0%)	44 (66%)	29 (62%)	.189	.695
High	41 (36.0%)	23 (34%)	18 (38%)		
Employment					
Yes	80 (70%)	50 (75%)	30 (64%)	1.539	.222
No	34 (30%)	17 (25%)	17 (36%)		
Living situation					
Living alone	23 (20%)	15 (22%)	8 (17%)	.515	.637
Cohabiting	93 (80%)	53 (78%)	40 (83%)		
Distance to training center (km)	5.5 (IQR 1.0-24.8)	5.0 (IQR 1.0-25.8)	7.0 (IQR 1.0-23.8)		
≤ 5	58 (50%)	35 (52%)	23 (48%)	1624.0	.962
6 -20	20 (17%)	11 (16%)	9 (19%)		
≥ 20	38 (33%)	22 (32%)	16 (33%)		
Disease-specific Characteristics					
NYHA class					
NYHA I-II	103 (93%)	61 (90%)	42 (98%)	2.501	.148
NYHA III-IV	8 (7%)	7 (10%)	1 (2%)		
Medication					
Yes	62 (56%)	38 (56%)	24 (56%)	.000	1.00
No	49 (44%)	30 (44%)	19 (44%)		
Surgery					
≤ 1	69 (62%)	39 (57%)	30 (70%)	1.726	.230
≥ 2	42 (38%)	29 (43%)	13 (30%)		
Diagnosis					
Mild	66 (60%)	44 (65%)	22 (51%)	2.245	.325
Moderate	35 (32%)	18 (27%)	17 (40%)		
Severe	10 (9%)	6 (9%)	4 (9%)		
Physical activity					
Physical activity score ≥ moderate intensity (guideline: score ≥ 50)*	25 (IQR 10-38)	19 (IQR 5-35)	33 (23-44)	977.0	.002‡
Compliant to guideline	19 (17%)	11 (17%)	8 (18%)		
Not compliant to guideline	92 (83%)	55 (83%)	37 (82%)		
Walking (min/wk)	60 (IQR 30-200)	60 (IQR 20-218)	70 (IQR 30-200)	1179.0	.534
Cycling (min/wk)	40 (IQR 10-120)	30 (IQR 0-130)	45 (IQR 18-120)	1242.0	.178

Demographic Characteristics	Total (n = 116)	GTI-yes (n = 68)	GTI-no (n = 48)	χ^2/ *U*	*P*
Physical fitness					
Grade physical fitness (0-10)†	6.0 (IQR 5.0-7.0)	6.0 (IQR 4.0-6.0)	7.0 (IQR 6.0-7.0)	861.5	<.001‡
Satisfaction physical fitness (0-10)†	5.0 (IQR 1.8-8.0)	4.0 (IQR 1.0-7.0)	7.0 (IQR 5.0-10.0)	707.0	<.001‡
Psychosocial determinants related to physical activity					
Motivation for physical activity in general (1-7)†	6.0 (IQR 5.3-7.0)	6.3 (IQR 5.7-7.0)	5.5 (IQR 5.0-6.0)	600.0	<.001‡
Self-efficacy (1-7)†	6.0 (IQR 4.7-6.7)	6.0 (IQR 5.0-7.0)	5.7 (IQR 4.7-6.0)	1194.0	.112
Negative social support (1-7)†	7.0 (IQR 5.9-7.0)	7.0 (IQR 5.9-7.0)	6.5 (IQR 5.6-7.0)	1312.5	.349
Positive social support (1-7)†	6.0 (IQR 5.0-7.0)	6.8 (IQR 5.5-7.0)	6.0 (IQR 5.0-6.5)	1064.0	.008‡

Data are presented as median (IQR) because of non-normality or number (percentage)
* Score = (frequency of moderate activity * 5 METs) + (frequency of vigorous activity * 9 METs); Score ≥ 50 equals the physical activity guideline of 30 min/d physical activities at least at moderate intensity.7
† A higher score indicates a more positive outcome.
‡Significant at 0.01 level (two tailed).
BMI, body mass index; GTI, GUCH Training Program-Individualised; IQR, interquartile range; METs, metabolic equivalent of tasks; NYHA, New York Heart Association.

Willingness to Participate in an Exercise Program

Of the 116 respondents, 93 (80%) were interested in improving their physical fitness and 23 (20%) were not. The main reasons for not being interested were satisfied with current physical fitness (43%) and lack of time (38%). Patients could be interested in improving their physical fitness but not willing to participate in GTI. In total, 68 respondents (59%) were willing to participate in GTI ('GTI-yes'), and 48 (41%) were not ('GTI-no') (Figure 1).

Determinants of Willingness to Participate in GTI

GTI-no patients were more physically active, had better perceived physical fitness, were more satisfied with their fitness level, were less motivated to be(come) physically active in general, and perceived less social support than GTI-yes patients (Table 1). There were no significant differences in other characteristics (Table 1).

To determine which determinants predict willingness to participate in GTI, logistic regression analyses were performed (method backward: LR) with the variables moderate-vigorous physical activity, perceived physical fitness, satisfaction with physical fitness, motivation for physical activity in general, and positive social support entered as independent variables. The best model included perceived physical fitness and motivation for physical activity in general:

*Predicted logit of (willingness to participate in GTI)= -3.652 + (-1.095*perceived physical fitness) + (1.785*motivation for physical activity in general).*

According to the model, the log odds of a patient willing to participate in GTI was negatively related to perceived physical fitness ($P < 0.001$) and positively related to motivation toward physical activity in general ($P < 0.001$) (Table 2). This model correctly predicted 81.1% of all cases, was significantly better than the null model, and fit the data well (Table 2).

2

Table 2 Logistic Regression Analysis Predicting Willingness to Participate in GTI

Predictor	B	SE *B*	Wald's χ^2	df	*P*	e^B (Odds Ratio)
Constant	-3.652	2.230	2.680	1	.102	.026
Perceived physical fitness	-1.095	.269	16.616	1	.000	.334
Motivation	1.785	.431	17.150	1	.000	5.960

Test	χ^2	df	*P*
Overall model evaluation			
Likelihood ratio test	46.488	2	.000
Goodness-of-fit test			
Hosmer and Lemeshow	3.995	8	.858

df, degree of freedom; GTI, GUCH Training Program-Individualised; SE, standard error.

Discussion and Conclusion

Previous research has indicated that most GUCH are interested in exercise and appropriate physical activity advice.[10, 18] However, the present study is the first study to examine their willingness to participate in an individualised tailor-made exercise program (GTI) and to identify factors that predict willingness to participate. It can be concluded that 59% of the respondents were willing to participate in GTI to improve exercise capacity. Their perceived physical fitness and motivation in relation to physical activity in general were the most important predictors of willingness to participate.

The main reason GUCH were not interested in improving their physical fitness was that they were satisfied with their physical fitness (43%). This was followed by a lack of time (38%) and disease-related symptoms (19%). This is little different than the findings of another study,[11] which concluded that disease-related symptoms (32%), followed by lack of interest in exercise (24%), were the most important barriers to exercise for GUCH. Only 5% of their participants listed ‘satisfaction with their current physical fitness’ a reason not to exercise. This apparent discrepancy with our findings might be due to the difference between willing *to exercise* and willing *to improve physical fitness*. The median score on perceived physical fitness of the participants in the present study was 6.0 (interquartile range 5.0-7.0) on a scale from 0 to 10. Other research showed that perceived physical fitness only poorly relates to actual physical fitness.[20] It should be noted that GUCH tend to overestimate their physical capacity.[20]

Patients willing to participate in GTI were less physically active, had lower perceived physical fitness, and were less satisfied with their fitness level than patients not willing to participate. This suggests that we succeeded in including patients in GTI for who GTI was originally developed. Strikingly, there were no significant differences in the demographics (e.g., age and distance to training center) and disease-specific characteristics (e.g., disease severity) of GTI-yes and GTI-no patients. Another recent study reported as well that young adults with congenital heart disease are interested to participate in an exercise program, regardless of long travel or other organizational difficulties.[5] The present study showed that the higher a patient perceived his/her physical fitness, the less likely the patients was willing to participate. If a patient was more motivated to engage in physical activity in general, he/she was more likely to participate in GTI. By assessing the willingness of GUCH to participate in an exercise program, we only assessed the *intention* to participate in an exercise program and not actual participation. However, according to the Theory of Planned Behavior intention to perform a specific behavior is the best predictor of actual performing that behavior.[21, 22] Whether the patients who were willing to participate would actual participate in the exercise program, should further research reveal.

Our results indicate that the majority of responding GUCH had a sedentary lifestyle. Only 17% of the respondents met the physical activity recommendation of at least 30 minutes per day of moderate to vigorous physical activity for most days of the week.[8] Our findings are comparable to those of another study, which found that only 14% of GUCH met the recommended physical activity level.[14] Similar results were found by Buys et al. who reported that only 19% of the GUCH participating in their study (n = 103) had a vigorously active lifestyle.[9] However, another study found a much higher percentage of patients meeting the recommended level of physical activity (76%).[23] More research is needed for an accurate view of physical activity levels in GUCH, but several studies showed that GUCH are less physically active than healthy adults.[9, 14] Furthermore, our results show that 50% of GUCH suffer from overweight or obesity, which is comparable with the healthy population.[24] Due to this unhealthy behaviour (overweight and sedentariness), GUCH have additional health risks. Therefore, it is important to promote in them a healthy lifestyle that includes physical activity and exercise. Because 59% of responding GUCH were willing to participate in GTI and taken into account number of nonrespondents, it would be worthwhile to examine whether other strategies promoting physical activity might attract more GUCH.

Some study characteristics should be taken into account when interpreting our results. The response rate was low (37%), which could have caused selection bias. Furthermore, physical activity and fitness were measured with a self-report questionnaire. Grown-ups with congenital heart disease are likely to overestimate their physical functioning.[20, 25] However, the way patients perceive themselves importantly reflects their quality of life or well-being[26] and provides valuable information. Although the short questionnaire to measure psychosocial determinants was based on the Theory of Planned Behaviour, for future research we recommend using questionnaires that have proven reliability and validity in the GUCH population.

In conclusion, overweight and sedentariness are highly prevalent in GUCH. Therefore, it is important to promote an active healthy lifestyle. Fifty-nine percent of our respondents were willing to participate in an exercise program. This illustrates that asking GUCH to participate in an exercise program supervised by physical therapists is a good strategy. Taken into account nonresponse, a participation rate in the exercise program of over 20% is to be expected. Perceived physical fitness and motivation to be(come) physically active in general were the most important predictors of willingness to participate. Other factors such as age, level of education, distance to the training center, and disease severity were not related to willingness to participate in an exercise program, which indicates that it is worthwhile to approach a wide range of patients for such an exercise program.

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3

Effect of diagnosis with a chronic disease on physical activity behaviour of middle-aged women

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Abstract

Objectives

(1) To describe changes in levels of physical activity in middle-aged women after diagnosis with a chronic disease; and (2) to examine whether physical activity levels are affected by the diagnosis.

Design

Observational study using data from 5 surveys (1998-2010) from the Australian Longitudinal Study on Women's Health (ALSWH). Participants completed surveys every three years, including questions about health, diseases, social circumstances, lifestyle, demographic factors and physical activity.

Setting

Population based cohort study of women in Australia.

Participants

Data were from 4840 middle-aged participants (born 1946-1951), who responded to at least one survey, did not report any chronic disease at baseline, but reported diagnosis with a chronic disease (i.e., heart disease, diabetes, asthma, breast cancer, arthritis, or depression) at any subsequent survey.

Main outcome measure

Leisure time physical activity, categorised as: nil/sedentary, low active, moderately active, highly active, based on MET.minutes per week spent walking and in moderate and vigorous activities.

Results

Between consecutive surveys, 41%-46% of the women did not change, 24%-30% decreased, and 24%-31% increased their physical activity level. These proportions of change were similar directly after diagnosis with a chronic disease, and in the years before or after diagnosis. Generalized estimating equations showed that there was no statistically significant effect of diagnosis with a chronic disease on level of physical activity.

Conclusions

Approximately half the middle-aged women were insufficiently active before diagnosis with a chronic disease. Despite the importance of physical activity in the management of chronic diseases, most women did not increase their physical activity after diagnosis. This illustrates a need for tailored interventions to enhance physical activity in newly diagnosed patients.

Introduction

Lifestyle adjustments are often necessary after diagnosis with a chronic disease, in order to reduce the likelihood of recurrence of an event or complications, decrease disease progression and increase or maintain quality of life.[1-3] For some chronic diseases, patients need to adhere to pharmaceutical prescriptions or adjust their eating habits, but for almost all conditions it is important for patients to be(come) regularly physically active.[4] With the exception of clinically unstable ischemic heart disease patients, physical activity is always preferable over being sedentary.[5, 6] Regular physical activity can decrease the progression or complications of many diseases.[4, 7] Moreover, it can improve patients' psychosocial well-being.[4, 8, 9]

To date, it is unclear whether newly diagnosed patients actually change their daily physical activity. Some studies suggest that patients become more physically active after having been diagnosed with a chronic disease,[10, 11] because they may experience their diagnosis as a 'wake-up call' for adopting a more healthy lifestyle. In contrast, other studies suggest that patients remain inactive or even become less physically active after having been diagnosed with a chronic disease,[12-15] possibly as a result of the physical or psychological limitations of their disease. For example, one study reported a small improvement in physical activity in newly diagnosed hypertensive patients,[11] whereas another study reported that following diagnosis with a vascular condition, including hypertension, patients did not increase their physical activity.[12] These inconsistencies suggest that it is unclear how patients respond to a chronic condition diagnosis, with respect to physical activity. Furthermore, research into 'post-diagnosis physical activity' is rather heterogeneous in terms of clinical definitions of physical activity. For example, some studies have examined changes in exercise,[15] whereas others have focused on changes in different types of leisure-time physical activities.[12, 14] As is the case for healthy adults, patients with a chronic disease are recommended to accumulate at least 30 minutes of moderate-intensity physical activity on most days of the week.[16] This can be achieved either by exercise, daily physical activities, or a combination of both.[17]

It is possible that changes in physical activity following diagnosis may vary between different chronic diseases,[13] because some diseases may result in more physical and/or psychological limitations and symptoms than others.[18] In addition, patients with certain conditions may be more likely to be encouraged by their clinician to become more physically active. Therefore, the present paper focuses on six of the most prevalent chronic diseases for which physical activity is known to be beneficial: heart disease, diabetes, asthma, breast cancer, arthritis and depression.[4, 19, 20]

The aims of this longitudinal study are to (1) describe changes in the level of physical activity in middle-aged women after diagnosis with a chronic disease (heart disease, diabetes, asthma, breast cancer, arthritis or depression); and to (2) examine whether level of physical activity is affected by the diagnosis.

Methods

Study design

Data from the Australian Longitudinal Study on Women's Health (ALSWH), a study that focusses on health and well-being of three birth cohorts of women, were used. For the ASLWH study, participants were randomly selected from the national Medicare health insurance database, which includes all Australian citizens and permanent residents. The ALSWH study was approved by the Ethics Committees of the Universities of Newcastle and Queensland and informed consent was obtained from all participants.[21] The women completed surveys every three years, including questions about health, symptoms and diagnoses of diseases, social circumstances, lifestyle, demographic factors and physical activity. Further details of the study can be found on www.alswh.org.au. In the present study, data from women in the middle-aged cohort (born 1946-1951) who responded to surveys in 1998 (T0), 2001 (T1), 2004 (T2), 2007 (T3) and 2010 (T4) were used. Number of respondents (and response rates relative to the first survey in 1996) per survey were 12338 (90%), 11226 (81.9%), 10905 (79.5%), 10638 (77.6%), and 10011 (73%), respectively.

Participants

Data from women who reported being diagnosed with heart disease, diabetes, asthma, breast cancer, arthritis or depression for the first time at T1, T2, T3 or T4 were included in the analyses. Women who did not report any of these chronic diseases in at least one of the surveys, who reported being diagnosed with heart disease, diabetes, asthma, breast cancer, or depression at T0 (arthritis was not assessed at T0), or who were non-respondent at all five surveys were excluded from the analysis sample.

Measurements

Chronic disease

At each survey, participants were asked whether they were, in the last three years, diagnosed with any of six chronic diseases selected from the Australian National Health Priority Areas (NHPA's) (ie, heart disease, diabetes, asthma, breast cancer, arthritis and depression).[20] These diseases are the most common chronic diseases and contribute significantly to the burden of disease both in Australia and in the rest of the world.[22] To deal with inconsistency in reporting chronic disease, the first time that a participant reported being diagnosed with one of the chronic diseases was considered as the actual diagnosis, even if there was no report of diagnosis with the disease in the next survey.

Physical activity

A modified version of the Active Australia Survey was used to measure physical activity in each survey.[23] This questionnaire assesses the frequency and total duration of walking, and of moderate and vigorous intensity leisure time physical activity during the last week. The reliability and validity of this questionnaire are shown to be acceptable in middle-aged women.[23] Physical activity was expressed in Metabolic Equivalent of Tasks (MET), in which 1 MET is the energy expenditure at rest. The total physical activity score, in MET minutes, was calculated using the following formula: *(3.0*minutes walking) + (4.0*minutes moderate activities) + (7.5*minutes vigorous activities)*. Based on this physical activity score, four ordered physical activity categories were created: 0-<40 MET minutes/week was defined as nil/sedentary; 40-<600 MET minutes/week as low; 600-<1200 MET minutes/week as moderate; and >=1200 MET minutes/week was defined as high level of physical activity.[24] Women in the moderate and high categories are meeting the physical activity guidelines of at least 150 minutes per week moderate intensity physical activity.[25]

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Possible related factors and covariates

The following socio-demographic, physical, psychological, and lifestyle factors were assessed at each survey unless stated otherwise: age, area of residence (rural, remote, urban), marital status (married/de facto; separated/divorced/widowed; single), body mass index (BMI) calculated using self-reported weight and height (kg/m2), menopausal status (pre-menopausal, peri-menopausal, post-menopausal, surgical menopause, undefined menopausal status due to hormone replacement therapy [HRT] or oral contraceptive [OCP] use [26]), stress, depressive symptoms (CES-D 10 [27, 28]), and smoking status (never smoked, ex-smoker and smoker). Education level was assessed at T4 (2010) and was categorized as: no formal qualification, school certificate, higher school certificate, trade/apprentice, certificate or diploma, university degree, and higher degree. Alcohol drinking status was assessed at each survey, except at T1. Participants were classified as non-risky drinker (non-drinker, rare drinker and low risk drinker) or risky drinker (risky drinker and high risk drinker). [29] Detailed information about the surveys and methods can be found on http://www.alswh.org.au/for-researchers/data.

Statistical analyses

All analyses were performed in the statistical programming language R [30]; p-values ≤ 0.05 were considered significant. Missing values for age were imputed by logical deductive reasoning. Because alcohol drinking status was fairly constant, missing values at T1 were imputed as follows: as most participants were non-risky drinkers, non-risky drinkers at T0 and/or T2 were also considered to be non-risky drinkers at T1; participants were considered as risky drinkers at T1, if they reported being risky drinkers at both T0 and T2. Descriptive statistics were used to examine the baseline characteristics of the study sample.

Changes in physical activity level before and after diagnosis with a chronic disease

The timing of being diagnosed with a chronic disease could vary between T1 and T4. The survey in which a woman reported a diagnosis of a chronic disease (i.e., diabetes, heart disease, asthma, breast cancer, arthritis or depression) for the first time was indicated as *adjusted time* 0. The survey prior to that survey was indicated as *adjusted time* -1; the survey following that survey as *adjusted time* +1; etc. (Table 1). The proportions of women who remained at the same physical activity level, who decreased, and who increased their physical activity level between the adjusted time periods were calculated. This was calculated for all chronic diseases, as well as for each chronic disease separately.

Table 1 Adjusted time-variable: Number of surveys relative to the survey in which diagnosis was reported for the first time.

Time	T0 (1998)	T1 (2001)	T2 (2004)	T3 (2007)	T4 (2010)
Diagnosed at T4	-4	-3	-2	-1	0
Diagnosed at T3	-3	-2	-1	0	+1
Diagnosed at T2	-2	-1	0	+1	+2
Diagnosed at T1	-1	0	+1	+2	+3

Effect of diagnosis with a chronic disease on level of physical activity

The effect of diagnosis with a chronic disease on physical activity level was analysed using generalized estimating equations for a cumulative logit model for repeated ordinal responses of physical activity using the MULTGEE package in R.[31] We corrected for the possible effects of factors and covariates including BMI, stress, depressive symptoms, time, smoking, alcohol drinking status, menopause, marital status, area of residence, and education. The covariates BMI, stress, and depressive symptoms were centred over time. Age was not included as a covariate since the range of the included participants is only five years and to avoid multi-collinearity with time. Partially, the outcomes of the analyses are cumulative odds ratios. To interpret these, it is important to keep in mind that cumulative odds ratios have the proportional odds property (Agresti, 2013, p.302). That is, given the scores on the explanatory variables, the cumulative odds ratio of a specific category of a factor is the odds for that specific category of being active at less than or equal to a certain level, divided by the odds of the reference (lowest) category of that factor of being active at less than or equal to the same level. For example, the probabilities of physical activity level 1 (nil/sedentary), 2 (low), 3 (moderate), and 4 (high) are respectively 0.24, 0.31, 0.18, and 0.27 for women with no formal education (education level 1). Consequently, the odds of physical activity level ≤ 2 for these women is $(0.24+0.31)/(0.18+0.27)= 1.22$. For women with a school certificate (education level 2) the probabilities of physical activity level 1, 2, 3, and 4 are respectively and 0.18, 0.31, 0.21, and 0.30. Consequently, the odds of physical activity level ≤ 2 for these women is $(0.18+0.31)/(0.21+0.30)= 0.96$. Dividing the odds of education level 2 by the odds of education level 1 (reference category) (0.96/1.22) results in a cumulative odds ratio of 0.79 for physical activity level ≤ 2 for women with education level 2 relative to education level 1 (reference). Such data driven odds ratios closely resemble those found by the cumulative logit model. It can be interpreted as follows: women with higher education have lower odds of low levels of physical activity than women with lower education.

For covariates (continuous variables), the cumulative odds ratio is proportional to the distance between the explanatory covariates: ie, for each unit of increase in the explanatory covariate, the cumulated odds ratio of being active at less than or equal to a certain level increases with the exponential of the estimated beta coefficient ($\exp(\beta)$). For example, an odds ratio of 1.06 for BMI means that per unit of BMI increase, the cumulative odds ratio of being physically active at less than or equal to a certain level increases by 1.06. This can be interpreted as follows: the odds of being inactive is higher for women with higher BMI.

The analyses were performed for incidence of all diseases, as well as for each chronic disease separately.

Results

Study sample

Out of 13715 women in the middle-aged ALSWH cohort, 4840 met the criteria for inclusion in this study and became the analysis sample. In 1998, the women were on average 49.6 ($\pm$ 1.5) years of age, had a mean (sd) BMI of 26.7 (5.3), and lived predominantly in rural areas (58.7%). Baseline characteristics of the analysis sample are presented in Table 2. The prevalence of any chronic disease increased from 48.7% to 68.8% between T1 and T4. Arthritis had the highest prevalence rate at each survey (34.8% - 48.7%), followed by depression (9.8%-13.0%) (Table 3).

Table 2 Baseline (T0, 1998) characteristics of the analysis sample (n = 4840)

Physical activity		
Physical activity level		
Nil/sedentary	n (%)	717 (17.5%)
Low	n (%)	1255 (30.6%)
Moderate	n (%)	914 (22.3%)
High	n (%)	1213 (29.6%)
Socio-demographic factors		
Age (in years)	mean (SD)	49.55 (1.45)
Marital status		
Married/De facto	n (%)	3711 (84.9%)
Separated/divorced/widowed	n (%)	527 (12.1%)
Single	n (%)	134 (3.1%)
Area of residence		
Urban	n (%)	1537 (35.1%)
Rural	n (%)	2567 (58.7%)
Remote	n (%)	271 (6.2%)
Education		
No formal	n (%)	617 (15.7%)
School certificate	n (%)	1020 (26.0%)
Higher school certificate	n (%)	776 (19.8%)
Trade/apprentice	n (%)	141 (3.6%)
Certificate/diploma	n (%)	665 (17.0%)
University degree	n (%)	410 (10.5%)
Higher degree	n (%)	292 (7.4%)
Physical factors		
BMI	mean (SD)	26.7 (5.3)
BMI category		
Underweight, BMI <18.5	n (%)	43 (1.1%)
Healthy weight, 18.5 ≤BMI<25	n (%)	1718 (43.5%)
Overweight, 25≤BMI<30	n (%)	1327 (33.6%)
Obese, 30≤BMI	n (%)	861 (21.8%)
Menopausal status		
Surgical menopause	n (%)	1195 (27.3%)
HRT/OCP use	n (%)	682 (15.6%)
Pre-menopausal	n (%)	981 (22.4%)
Peri-menopausal	n (%)	1073 (24.5%)
Post-menopausal	n (%)	445 (10.2%)
Psychological factors		
Stress	mean (SD)	0.58 (0.46)
Depressive symptoms	mean (SD)	5.96 (5.05)
Lifestyle factors		
Smoking status		
Never smoked	n (%)	2376 (56.4%)
Ex-smoker	n (%)	1154 (27.4%)
Smoker	n (%)	680 (16.2%)
Alcohol drinking status		
Non-to-low-risk drinker	n (%)	3955 (94.0%)
Risk-to high risk drinker	n (%)	254 (6.0%)

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Table 3 Prevalence of chronic diseases in middle-aged women

	T0[a] (1998)	T1 (2001)	T2 (2004)	T3 (2007)	T4 (2010)
Chronic disease, n (%)	0 (0%	2124 (48.7%)	2458 (57.2%)	2760 (64.1%)	2813 (68.8%)
Diabetes, n (%)	0 (0%	101 (2.3%)	183 (4.3%)	327 (7.6%)	390 (9.5%)
Heart disease, n (%	0 (0%	76 (1.7%)	131 (3.0%)	206 (4.8%)	227 (5.5%)
Asthma, n (%)	0 (0%	224 (5.1%)	280 (6.5%)	329 (7.6%)	341 (8.3%)
Breast cancer, n (%)	0 (0%	76 (1.7%)	109 (2.5%)	150 (3.5%)	159 (3.9%)
Depression, n (%)	0 (0%	429 (9.8%)	558 (13.0%)	601 (13.9%)	533 (13.0%)
Arthritis, n (%)	N/A[b]	1518 (34.8%)	1709 (39.8%)	1899 (44.1%)	1994 (48.7%)

[a] Women with chronic disease at T0 were excluded from the analyses.
[b] Arthritis was not assessed at T0

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Changes in physical activity level over time before and after diagnosis with a chronic disease

The changes in level of physical activity between subsequent surveys are visually presented in Figure 1. It shows the proportions of women who remained at the same level, and the proportions who decreased, and who increased their physical activity level between two surveys, relative to the survey in which they reported being diagnosed with a chronic disease for the first time (-1 to 0).

Over each adjusted time interval, 41% to 46% of women did not change their physical activity level. From directly before to directly after diagnosis of any chronic disease (from 1 survey prior to diagnosis, to the survey of first report of diagnosis), 42% of the women did not change their physical activity level. More in-depth analysis showed that 15% of these 'no-changers' were categorised as sedentary, 33% as low active, 15% as moderately active, and 37% as highly active. Between 24% and 30% of women decreased their physical activity level between subsequent surveys. Most of the women who decreased their level of physical activity directly after being diagnosed with any chronic disease were highly physically active before diagnosis (52%). Thirty percent were moderately active before diagnosis, and 18% were low active. Furthermore, Figure 1 shows that 24% to 31% of women increased their physical activity level between two surveys. More specifically, from directly before to directly after diagnosis, 30% increased their level of physical activity. Of these, 35% were sedentary before diagnosis, 40% were low active, and 25% were moderately active. There were no noticeable differences in the aforementioned proportions between the time transition from directly before to directly after diagnosis (time transition from -1 to 0) and between time transitions in the years before or after diagnosis (Figure1).

The percentage of women who remained or became physically active at the recommended level fluctuated around 50% at each time transition.

Table 4 shows the proportions of women who increased and decreased their physical

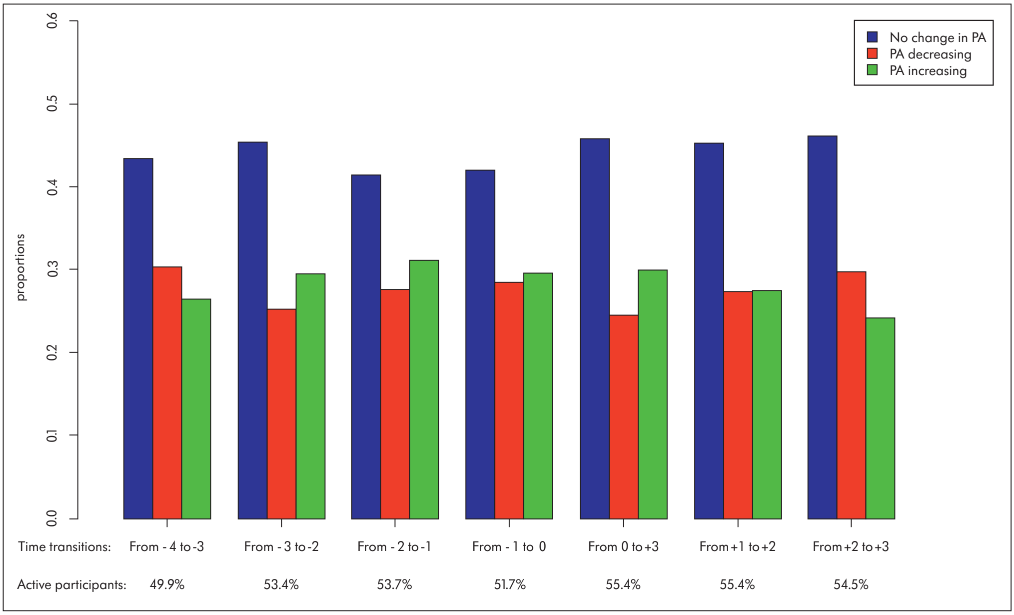

Figure 1 Proportions of women with a chronic disease in each 'physical activity change- between-two-surveys category' (ie, no change in physical activity level, increase, or decrease in physical activity level) at each time transition.

- 0 represents the survey in which the diagnosis was reported for the first time, -1 represents the survey prior to diagnosis, -2 represents two surveys prior to diagnosis, +1 represents the survey following diagnosis, etc.
- Bars at -1 to 0 show the proportion of participants who did not change, who decreased, and who increased their level of physical activity directly after being diagnosed with a chronic disease.
- Active participants = participants with physical activity level 3 or 4 at 3, 2, 1 surveys prior to diagnosis, at survey of diagnosis, and 1, 2, 3 surveys following diagnosis, respectively.

activity level in more detail. The largest proportion of participants remained at a stable level between two surveys, with most proportions ranging between 37% and 49%. The proportion of participants who decreased their physical activity level between two surveys ranged from 22% to 34%. Of those who increased their physical activity, proportions ranged from 24% and 36%, except for one outlier (15%). There were almost no notable differences in proportions of change between the different diseases. Exceptions were a relatively small proportion of women increased their physical activity level after being diagnosed with heart disease (15% to 26%), and a relatively large proportion of women remained at a stable level of physical activity in the years following diagnosis of heart disease (49% to 57%). In addition, after being diagnosed with breast cancer, a relatively large proportion of women increased their physical activity level (35%) and a relatively small proportion of women decreased their physical activity level (22%).

Table 4 Proportion of participants who decreased and increased their level of physical activity per adjusted time transition before and after being diagnosed with any chronic disease, heart disease, diabetes, asthma, breast cancer, depression, or arthritis.

Time transition		Proportion of participants who decreased/increased their physical activity						
From	**To**	**Chronic disease***	**Heart disease**	**Diabetes**	**Asthma**	**Breast cancer**	**Depression**	**Arthritis**
4 surveys prior diagnosis	3 surveys prior diagnosis	0.30/0.26	0.31/0.26	0.34/0.27	0.33/0.25	0.33/0.31	0.32/0.30	0.29/0.28
3 surveys prior diagnosis	2 surveys prior diagnosis	0.25/0.29	0.30/0.35	0.29/0.33	0.32/0.27	0.28/0.26	0.30/0.32	0.25/0.31
2 surveys prior diagnosis	1 survey prior diagnosis	0.28/0.31	0.28/0.33	0.33/0.31	0.27/0.30	0.23/0.33	0.31/0.31	0.26/0.31
1 survey prior diagnosis	(0) survey of diagnosis	0.28/0.30	0.28/0.30	0.26/0.36	0.30/0.28	0.29/0.21	0.29/0.32	0.29/0.28
(0) survey of diagnosis	1 survey following diagnosis	0.24/0.30	0.29/0.21	0.29/0.28	0.26/0.34	0.22/0.35	0.27/0.32	0.24/0.29
1 survey following diagnosis	2 surveys following diagnosis	0.27/0.27	0.25/0.26	0.34/0.19	0.29/0.30	0.30/0.29	0.29/0.26	0.26/0.28
2 surveys following diagnosis	3 surveys following diagnosis	0.30/0.24	0.28/0.15	0.34/0.27	0.34/0.24	0.24/0.26	0.29/0.27	0.30/0.24

*a chronic disease = heart disease, diabetes, asthma, breast cancer, depression, or arthritis

Effect of diagnosis with a chronic disease on level of physical activity

The resulting estimates of the models from the repeated ordinal physical activity responses are given in Table 5. The main result is that all levels of the variable 'time prior and following diagnosis' had no significant effect on the level of physical activity. For example, at the time of the survey with reported diagnosis, the cumulative odds of lower levels of physical activity compared with higher levels is 0.93 times that of 4 surveys prior to diagnosis. This can be interpreted as follows: the odds of being inactive seemed to be lower at the time of diagnosis than at 4 surveys (± 12 years) prior to diagnosis. However, this was not statistically significant. Thus, Table 5 shows that we found no evidence for a significant effect of diagnosis with a chronic disease on level of physical activity, neither directly after diagnosis, nor in the surveys prior to or following the diagnosis. In contrast, time, education level, BMI, depressive symptoms, and smoking status had a significant effect on physical activity level.

Table 5 shows that for women with a chronic disease, the cumulative odds of lower physical activity levels versus higher physical activity levels at T1 is 1.18 times that at T0, and at T3, the cumulative odds is 0.82 times that at T0. In short, compared with T0, the odds of being inactive

Table 5 Effect of diagnosis with a chronic disease on level of physical activity after adjustment for socio-demographic -, physical -, psychological-, and lifestyle factors and covariates, analysed by generalized estimating equations with a cumulative logit model of the repeated ordinal responses of physical activity. (Complete table as appendix)

Chronic disease[a]	β	95% Confidence Interval		cOR*
		Lower bound	Upper bound	
DIAGNOSIS OF A CHRONIC DISEASE				
Time prior and following diagnosis (reference category: 4 surveys prior diagnosis)				
3 surveys prior diagnosis	0.014	-0.170	0.197	1.01
2 surveys prior diagnosis	-0.014	-0.196	0.167	0.99
1 survey prior diagnosis	-0.062	-0.249	0.125	0.94
Survey of diagnosis	-0.072	-0.284	0.139	0.93
1 survey following diagnosis	-0.081	-0.314	0.153	0.92
2 surveys following diagnosis	-0.016	-0.274	0.241	0.98
3 surveys following diagnosis	0.035	-0.254	0.325	1.04
SOCIO-DEMOGRAPHIC FACTORS				
Time with 3 years interval (reference category: T0 [1998])				
T1 (2001)	0.166	0.073	0.259	1.18
T2 (2004)	-0.048	-0.168	0.071	0.95
T3 (2007)	-0.203	-0.353	-0.053	0.82
T4 (2010)	-0.103	-0.284	0.078	0.90
Education level (reference category: no formal qualification)				
School certificate	-0.208	-0.344	-0.071	0.81
Higher school certificate	-0.216	-0.358	-0.073	0.81
Trade/apprentice	-0.289	-0.540	-0.039	0.75
Certificate/diploma	-0.404	-0.551	-0.256	0.67
University degree	-0.435	-0.603	-0.267	0.65
Higher degree	-0.335	-0.519	-0.150	0.72
PHYSICAL FACTORS				
BMI (range -14.4 – 36.1)	0.059	0.052	0.067	1.06
PSYCHOLOGICAL FACTORS				
Depressive symptoms (CES-D) (range -5.99 – 24.01)	0.041	0.034	0.049	1.04
LIFESTYLE FACTORS				
Smoking status (reference category: never smoked)				
Ex-smoker	-0.093	-0.177	-0.008	0.91
Current smoker	0.227	0.105	0.350	1.25

Corrected for marital status, area of residence, menopausal status, stress, and alcohol drinking status.
a = heart disease, diabetes, asthma, breast cancer, depression, or arthritis
* cOR = Cumulative odds ratio=
For categorical variables: the cumulative odds ratio of a specific category of a factor is the odds for that specific category of being active at less than or equal to a certain level divided by the odds of the reference (lowest) category of that factor of being active at less than or equal to the same level.
For continuous variables: For each unit increase of the explanatory covariate the cumulated odds ratio of being active at less than or equal to a certain level increases with the exponential of the estimated beta coefficient (exp(β).
β ; estimate

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were higher at T1 and lower at T3. Each level of education had a significant effect on the log odds of physical activity levels. For example, the cumulative odds of lower physical activity levels versus higher physical activity levels for women with a higher university degree is 0.72 times that of women with no formal qualification. In short, the odds of being inactive is lower for more highly educated women than for women with low education. BMI had a significant effect on the level of physical activity as well. The centred BMI ranged from -14.4 to 36.1. Per unit of BMI increase, the cumulative odds ratio of being physically active at less than or equal to a certain level increased by 1.06. In short, the odds of being inactive was higher for women with higher levels of BMI. The centred CES-D (depressive symptoms) ranged from -5.99 to 24.0. Per unit of CES-D increase, the cumulative odds ratio of being physically active at less than or equal to a certain level increased by 1.04, which can be interpreted as higher odds of being inactive among women with more depressive symptoms. Furthermore, the odds of being inactive was lower for ex-smokers and higher for current smokers than for women who never smoked.

When analysing the effect of diagnosis of each specific disease, the results remained more or less the same. There was no effect of being diagnosed with diabetes, heart disease, asthma, breast cancer, depression, or arthritis on level of physical activity. BMI, level of education and depressive symptoms had a significant effect on level of physical activity for each disease, except in patients with breast cancer, whose physical activity level was not affected by education level. More details are presented in the appendix.

Discussion

This longitudinal study of middle aged women demonstrated that most women remain at the same level of physical activity after being diagnosed with heart disease, diabetes, asthma, breast cancer, arthritis, or depression. Although approximately 54% of the women increased or decreased their level of physical activity after diagnosis, the pattern of change was no different around time of diagnosis than between any other two pairs of surveys in the years before or after diagnosis. The present study provides evidence that physical activity level is not affected by diagnosis with a chronic disease, but is affected by factors such as level of education, time, body mass index, depressive symptoms and smoking status.

Previous research, in which changes in physical activity in newly diagnosed patients was examined by comparing the proportions of sedentary participants before and after diagnosis, suggested that there is no change, or a decrease in physical activity after diagnosis with a chronic disease.[13-15] The study by Van Gool et al. (2007) found an increase in the proportion of sedentary subjects after diagnosis with a chronic disease, compared with before diagnosis, which suggests that newly diagnosed patient decrease their physical activity.[13] In contrast, the study by Newsom et al. (2012) showed that approximately 50% of the participants were sedentary before and after diagnosis with a chronic disease.[14] Hence there was no change in physical activity after diagnosis with a chronic disease.[14] However, in both these studies some patients might have increased their physical activity, while others might have decreased, thus cancelling any effects. Furthermore, changes could have been too small to detect with this method of analysing change. Another study examined changes in physical activity in newly diagnosed patients, by calculating the proportions of people who remained inactive or active, and who became inactive or active when diagnosed with a vascular condition.[12] It was shown that 70% did not change their level of physical activity, but about 30% became active or inactive.[12] However, because they used rather crude categories (active vs inactive), it is possible that patients changed their physical activity, but not enough to result in a lower or higher category. A strength of the current study is that physical activity was categorised into four levels. Moreover, the cut-offs were based on clinically meaningful differences in the levels of physical activity, which increases the likelihood of picking up clinically relevant changes in level of physical activity. Approximately 44% did not change their level of physical activity. This lack of change occurred at all levels of physical activity, from sedentary to highly active. Just over half the study sample changed their physical activity level, with approximately equal proportions increasing and decreasing.

The results of this study showed that this pattern of change was no different around the time of diagnosis than between any other two subsequent surveys, before and after diagnosis. There was no effect of diagnosis with a chronic disease on level of physical activity, but more generic factors did affect the level of physical activity. Older women, and women with a higher level of education, lower body mass index, less depressive symptoms, and women who ceased smoking had lower odds of low levels of physical activity. Although physical activity typically declines with age, the time related effects on physical activity levels suggested that this was not a linear relationship. The finding that women had higher odds of being physically inactive at T1 and lower odds at T3 may be explained by the transition to retirement, with more time for leisure time activities.[32, 33] The level of education effect showed that the odds of low levels of physical activity was lower for highly educated than for low educated women. This is in line with the literature.[34-38] The current study, as well as other studies, showed that, compared with women who never smoked, current smokers had higher odds of low levels of physical activity and ex-smokers had lower odds of low levels of physical activity.[12] Perhaps there is a clustering of healthy behaviours,[12, 39] but more research is necessary to establish the direction and interaction of these relationships between different healthy behaviours. Furthermore, our results confirmed findings of other studies that women with a high BMI are more likely to have low levels of physical activity than women with a low BMI.[36, 40-42] In addition, women with more depressive symptoms were more likely to have low levels of physical activity than those with fewer depressive symptoms. However, it is known that depressive symptoms often occur when a chronic disease is diagnosed.[43, 44] Therefore, it could be that the effect of depressive symptoms on level of physical activity was genuinely the effect of depressive symptoms and not the indirect effect of diagnosis with a chronic disease. However, post-hoc analyses revealed no effect of diagnosis with a chronic disease on physical activity in the model when depressive symptoms was excluded from the analysis. Physical activity is a complex behaviour, and many other factors are often found to be related to it.[34, 35, 45-47] More research is necessary to fully understand the complexity of (changes in) physical activity behaviour and its determinants in newly diagnosed patients.

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The present study showed that, despite the well-known benefits of physical activity in the treatment of chronic diseases,[4, 7] about 50% of newly diagnosed patients were not meeting the recommended levels of physical activity.[16, 25] This is in line with findings of other studies.[14, 15] The large proportion of inactive patients illustrates deficiencies in current efforts to encourage patients to adopt more active lifestyles. Although we do not know whether any advices had been offered to the newly diagnosed patients by their health care providers, other studies have shown that it is not always routine clinical practice to give physical activity advice and encourage patients to become more physically active, despite the recommendations in clinical guidelines. For example, one study showed that 39% of patients with heart failure had not received physical activity advice from their cardiologist.[45] Another study reported that 37% of patients with congenital heart disease did not receive physical activity advice from their cardiologist.[48]

When interpreting the results of the present study, some strengths and limitations should be taken into account. Strengths include the large sample, and the prospective study design. Furthermore, the present study showed changes in physical activity from 12 years prior to diagnosis to 9 years following diagnosis with a chronic disease. In addition, this study examined change in physical activity associated with six common chronic diseases. However, it should be noted that diagnosis was based on self-report. Some studies have suggested that self-report measures of diagnosis with a chronic disease are fairly accurate,[49, 50] although this can be influenced by fluctuations in symptoms.[51] Other studies have suggested that self-report measures of diagnosis should be interpreted with caution,[52] and have stressed for the likelihood of underreporting chronic diseases.[53, 54] However, if the self-report measures biased the results in the present study, this would have resulted in an underestimation of the total number of women diagnosed with a chronic disease. Furthermore, diagnosis with arthritis was not assessed at T0, which may have led to underreporting as well. However, we found no deviating results in women who reported being diagnosed with arthritis at some point in time, compared with women diagnosed with another disease. As participants were asked whether they had been diagnosed with a chronic disease in the past three years, they would have been diagnosed between three years and one day prior to survey completion. In cases where the survey was completed a long time after diagnosis, any potential acute behavioral change may have reverted back to the pre-diagnosis physical activity level. Alternatively, in cases where the survey was completed a very short time after diagnosis, there may not have been enough time for a change in behavior. Furthermore, physical activity was measured with a self-report method. Although the validity and reliability of self-report measures is generally lower than objective measures of physical activity,[55] self-report measures can be used to accurately classify respondents' level of physical activity.[56] However, the questionnaire might not have been sensitive enough to capture all changes in physical activity. Future research should use objective and performance-based measures of physical activity that are more sensitive to subtle changes in physical activity.

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In conclusion, approximately half these middle-aged women were insufficiently active before diagnosis with a chronic disease. Despite the important role of physical activity in the management of chronic diseases, most women did not increase their physical activity after diagnosis. This illustrates a need for tailored interventions to enhance physical activity in newly diagnosed patients. Physical activity is not affected by diagnosis with a chronic disease, but rather by more generic factors such as level of education and body mass index. Further research, preferably with accelerometer measured activity, may reveal additional factors which impact on physical activity behaviour in newly diagnosed patients.

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What is already known on this subject

- For (almost) all patients with a chronic disease it is important to be(come) regularly physically active.
- Some studies suggest that patients become more physically active after having been diagnosed with a chronic disease, whereas other studies suggest that patients remain inactive or even become less physically active after having been diagnosed with a chronic disease.
- To date, it is unclear how patients respond to a chronic condition diagnosis, with respect to physical activity.

What this study adds

- This study shows that physical activity level is not affected by diagnosis with a chronic disease, but rather by more generic factors such as level of education and BMI.
- Despite the important role of physical activity in the management of chronic diseases, approximately half the participants were insufficiently active and most women did not increase their physical activity after diagnosis.
- The findings of this study illustrate a need for tailored interventions to enhance physical activity in newly diagnosed patients.

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Table 5 Effect of diagnosis with a chronic disease on level of physical activity after adjustment for socio-demographic -, physical -, psychological-, and lifestyle factors and covariates, analysed by generalized estimating equations with a cumulative logit model of the repeated ordinal responses of physical activity.

	Chronic disease[a]			Diabetes			Heart disease		
Variables	β	*p*	cOR*	β	*p*	cOR*	β	*p*	cOR*
DIAGNOSIS OF A CHRONIC DISEASE									
Time prior and following diagnosis (reference category: 4 surveys prior diagnosis)									
3 surveys prior diagnosis	0.014	0.885	1.01	-0.112	0.564	0.89	0.389	0.071	1.48
2 surveys prior diagnosis	-0.014	0.877	0.99	-0.195	0.382	0.82	0.402	0.091	1.49
1 survey prior diagnosis	-0.062	0.514	0.94	-0.019	0.939	0.98	0.388	0.137	1.47
Survey of diagnosis	-0.072	0.503	0.93	-0.251	0.379	0.78	0.356	0.238	1.43
1 survey following diagnosis	-0.081	0.498	0.92	-0.326	0.325	0.72	0.532	0.132	1.70
2 surveys following diagnosis	-0.016	0.901	0.98	0.146	0.701	1.16	0.366	0.370	1.44
3 surveys following diagnosis	0.035	0.810	1.04	0.056	0.901	1.06	0.507	0.298	1.66
SOCIO-DEMOGRAPHIC FACTORS									
Time with 3 years interval (reference category: T0 [1998])									
T1 (2001)	0.166	<0.001	1.18	0.296	0.044	1.34	-0.029	0.863	0.97
T2 (2004)	-0.048	0.427	0.95	-0.005	0.980	1.00	-0.069	0.732	0.93
T3 (2007)	-0.203	0.008	0.82	-0.132	0.566	0.88	-0.347	0.160	0.71
T4 (2010)	-0.103	0.266	0.90	0.046	0.867	1.05	0.035	0.908	1.04
Marital status (reference category: married/ de facto)									
Separated/divorced/widowed	-0.071	0.143	0.93	-0.15	0.286	0.86	-0.208	0.118	0.81
Single	0.202	0.102	1.22	-0.119	0.762	0.89	0.190	0.529	1.21
Area of residence (reference category: rural)									
Remote	0.031	0.446	1.03	0.204	0.077	1.23	-0.092	0.479	0.91
Urban	0.035	0.680	1.04	0.125	0.633	1.13	-0.262	0.315	0.77
Education level (reference category: no formal qualification)									
School certificate	-0.208	0.003	0.81	-0.374	0.031	0.69	-0.529	0.007	0.59
Higher school certificate	-0.216	0.003	0.81	-0.266	0.170	0.77	-0.456	0.057	0.63
Trade/apprentice	-0.289	0.024	0.75	0.185	0.614	1.20	-1.472	<0.001	0.23
Certificate/diploma	-0.404	<0.001	0.67	-0.078	0.692	0.92	-0.765	0.001	0.47
University degree	-0.435	<0.001	0.65	-0.613	0.024	0.54	-0.970	<0.001	0.38
Higher degree	-0.335	<0.001	0.72	0.251	0.358	1.28	-0.138	0.562	0.87
PHYSICAL FACTORS									
BMI (range -14.4 – 36.1)	0.059	<0.001	1.06	0.068	<0.001	1.07	0.044	<0.001	1.04
Menopausal status (reference category: pre-menopausal status)									
Peri-menopausal status	0.015	0.805	1.02	-0.292	0.136	0.75	0.091	0.649	1.10
Post-menopausal status	0.090	0.221	1.09	0.314	0.139	1.37	0.059	0.811	1.06

3

Asthma			Breast cancer			Depression			Arthritis		
β	*p*	cOR*	β	*p*	cOR*	β	*p*	cOR*	β	*p*	cOR*
-0.129	0.539	0.88	-0.226	0.344	0.80	0.045	0.792	1.05	-0.042	0.681	0.96
-0.078	0.725	0.92	-0.005	0.985	1.00	0.159	0.364	1.17	-0.125	0.224	0.88
-0.356	0.109	0.70	-0.348	0.269	0.71	0.167	0.353	1.18	-0.146	0.169	0.86
-0.399	0.118	0.67	0.080	0.821	1.08	0.053	0.795	1.05	-0.060	0.619	0.94
-0.517	0.074	0.60	-0.418	0.303	0.66	0.077	0.728	1.08	-0.076	0.573	0.93
-0.617	0.059	0.54	-0.063	0.891	0.94	0.063	0.796	1.07	-0.073	0.621	0.93
-0.485	0.195	0.62	-0.370	0.476	0.69	0.006	0.982	1.01	-0.086	0.608	0.92
0.298	0.018	1.35	0.195	0.272	1.22	0.042	0.652	1.04	0.152	0.006	1.16
0.150	0.360	1.16	0.005	0.985	1.01	-0.113	0.328	0.89	-0.069	0.328	0.93
0.081	0.681	1.08	-0.138	0.649	0.87	-0.031	0.833	0.97	-0.231	0.009	0.79
0.301	0.200	1.35	-0.004	0.992	1.00	0.043	0.803	1.04	-0.080	0.451	0.92
-0.172	0.153	0.84	-0.004	0.981	1.00	0.088	0.252	1.09	-0.084	0.150	0.92
0.602	0.185	1.83	-0.674	0.193	0.51	0.384	0.088	1.47	0.242	0.074	1.27
0.031	0.783	1.03	-0.002	0.989	1.00	0.019	0.807	1.02	-0.018	0.699	0.98
0.253	0.207	1.29	0.189	0.558	1.21	0.053	0.751	1.05	0.125	0.213	1.13
-0.405	0.025	0.67	0.029	0.927	1.03	-0.181	0.139	0.83	-0.289	<0.001	0.75
-0.354	0.076	0.70	0.502	0.114	1.65	-0.432	0.001	0.65	-0.195	0.019	0.82
-0.603	0.037	0.55	0.551	0.197	1.73	-0.078	0.718	0.92	-0.375	0.008	0.69
-0.622	0.001	0.54	-0.342	0.291	0.71	-0.313	0.015	0.73	-0.445	<0.001	0.64
-0.585	0.012	0.56	-0.009	0.980	0.99	-0.628	<0.001	0.53	-0.434	<0.001	0.65
-0.291	0.301	0.75	0.221	0.562	1.25	-0.276	0.107	0.76	-0.426	<0.001	0.65
0.065	<0.001	1.07	0.077	<0.001	1.08	0.062	<0.001	1.06	0.064	<0.001	1.07
-0.084	0.605	0.92	0.026	0.912	1.03	0.092	0.413	1.10	0.015	0.824	1.02
-0.226	0.240	0.80	0.368	0.204	1.44	0.146	0.318	1.16	0.120	0.168	1.13

Variables	Chronic disease[a] β	p	cOR*	Diabetes β	p	cOR*	Heart disease β	p	cOR*
Surgical menopause	0.076	0.200	1.08	0.189	0.264	1.21	0.204	0.296	1.23
HRT/OCP	-0.022	0.633	0.98	0.092	0.489	1.10	-0.113	0.415	1.51
PSYCHOLOGICAL FACTORS									
Stress (range -0.56 – 3.44)	0.053	0.211	1.05	0.022	0.857	1.02	0.108	0.378	1.11
Depressive symptoms (CES-D) (range -5.99 – 24.01)	0.041	<0.001	1.04	0.032	0.005	1.03	0.055	<0.001	1.06
LIFESTYLE FACTORS									
Smoking status (reference category: never smoked)									
Ex-smoker	-0.093	0.032	0.91	0.249	0.044	0.78	-0.032	0.798	0.97
Current smoker	0.227	<0.001	1.25	0.075	0.690	1.08	0.080	0.665	1.08
Alcohol drinking status (reference category: non-risky drinker)									
Risky drinker	-0.030	0.690	0.97	0.170	0.471	1.19	0.143	0.533	1.15
PHYSICAL ACTIVITY									
PA levels (reference category: PA level 4)									
Intercept PA level 1	-1.369	<0.001	0.25	-1.28	<0.001	0.28	-1.225	<0.001	0.29
Intercept PA level 2	0.193	0.079	1.21	0.358	0.124	1.43	0.292	0.266	1.30
Intercept PA level 3	1.163	<0.001	3.20	1.402	<0.001	4.06	1.258	<0.001	3.52

a = heart disease, diabetes, asthma, breast cancer, depression, or arthritis
* cOR = Cumulative odds ratio=
For categorical variables: the cumulative odds ratio of a specific category of a factor is the odds for that specific category of being active at less than or equal to a certain level divided by the odds of the reference (lowest) category of that factor of being active at less than or equal to the same level.
For continuous variables: For each unit increase of the explanatory covariate the cumulated odds ratio of being active at less than or equal to a certain level increases with the exponential of the estimated beta coefficient (exp(β)).
β; estimate, PA; physical activity

3

Asthma			Breast cancer			Depression			Arthritis		
β	*p*	cOR*	β	*p*	cOR*	β	*p*	cOR*	β	*p*	cOR*
-0.009	0.959	0.99	0.364	0.125	1.44	0.065	0.571	1.07	0.130	0.056	1.14
-0.078	0.520	0.92	-0.077	0.671	0.93	-0.083	0.335	0.92	-0.011	0.843	0.99
0.026	0.823	1.03	0.001	0.996	1.00	-0.113	0.112	0.89	0.125	0.012	1.13
0.045	<0.001	1.05	0.048	0.001	1.05	0.039	<0.001	1.04	0.040	<0.001	1.04
0.064	0.586	1.07	-0.018	0.904	0.98	-0.206	0.017	0.81	-0.094	0.058	0.91
0.526	0.001	1.69	0.412	0.062	1.51	0.188	0.098	1.21	0.181	0.015	1.20
-0.495	0.012	0.61	-0.140	0.575	0.87	-0.059	0.660	0.94	0.019	0.834	1.02
-1.062	<0.001	0.35	-1.823	<0.001	0.16	-1.314	<0.001	0.27	-1.237	<0.001	0.29
0.526	0.040	1.69	-0.362	0.347	0.70	0.206	0.286	1.23	0.325	0.008	1.38
1.530	<0.001	4.62	0.680	0.076	1.97	1.202	<0.001	3.33	1.271	<0.001	3.56

4

Daily physical activity in stable heart failure patients

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Abstract

Background

Physical activity is the only nonpharmacological therapy that is proven to be effective in heart failure (HF) patients in reducing morbidity. To date, little is known about the levels of daily physical activity in HF patients and about related factors.

Objective

The objectives of this study were to (*a*) describe performance-based daily physical activity in HF patients, (*b*) compare it with physical activity guidelines, and (*c*) identify related factors of daily physical activity.

Methods

The daily physical activity of 68 HF patients was measured using an accelerometer (SenseWear) for 48 hours. Psychological characteristics (self-efficacy, motivation, and depression) were measured using questionnaires. To have an indication how to interpret daily physical activity levels of the study sample, time spent on moderate- to vigorous-intensity physical activities was compared with the 30-minute activity guideline. Steps per day was compared with the criteria for healthy adults, in the absence of HF-specific criteria. Linear regression analyses were used to identify related factors of daily physical activity.

Results

Forty-four percent were active for less than 30 min/d, whereas 56% were active for more than 30 min/d. Fifty percent took fewer than 5000 steps per day, 35% took 5000 to 10 000 steps per day, and 15% took more than 10 000 steps per day. Linear regression models showed that New York Heart Association classification and self-efficacy were the most important factors explaining variance in daily physical activity.

Conclusions

The variance in daily physical activity in HF patients is considerable. Approximately half of the patients had a sedentary lifestyle. Higher New York Heart Association classification and lower self-efficacy are associated with less daily physical activity. These findings contribute to the understanding of daily physical activity behavior of HF patients and can help healthcare providers to promote daily physical activity in sedentary HF patients.

Keywords

Health behavior; Heart failure; Motor activity; Self-efficacy.

Introduction

Heart failure (HF) is one of the most prevalent cardiovascular syndromes all over the world, and has a poor long term prognosis.[1] Promoting physical activity is an important treatment strategy[2, 3] because it reduces mortality, hospitalizations, and risk for other chronic diseases.[4] Furthermore, physical activity decreases progression of the disease, risk of functional limitations, and loss of independence and improves quality of life.[2, 4, 5]

Studies on HF patients have demonstrated that exercise is beneficial.[2, 4, 5] However, not every HF patient is capable of engaging in exercise. Moreover, adherence to exercise is a problem.[5-7] We suggest that daily physical activity can be considered as an alternative to exercise because research suggests that daily physical activity has positive effects in HF patients as well.[8, 9] One study, for example, showed that by increasing walking duration from 10 to 60 min/d, HF patients can improve exercise capacity and general well-being.[8] Another study showed that reduced daily physical activity is a strong predictor of mortality.[9] Because daily physical activity includes occupational, leisure time, household, personal care, and transportation activities,[10] it may be easier to fit into daily life than exercise.

Several daily physical activity guidelines recommend HF patients to perform at least 30 min/d of physical activities at moderate intensity on most days of the week.[3, 11-13] Although several studies have suggested that daily physical activity levels in HF patients are low,[9, 14, 15] it is unclear whether these daily physical activity guidelines are followed. Most studies used only small sample sizes, self-report measurements, or outcome measures that were incomparable with physical activity recommendations.[15, 16] The use of accelerometers, instead of questionnaires, is preferred because it can give insight into daily physical activity in a performance-based manner and can offer specific and more reliable information about the pattern, duration, and intensity of daily physical activity throughout the day and about patient adherence.[17] To date, the prevalence of physical activity levels in HF patients, whether physically active or sedentary, are unknown. Patients are physically active when they perform more than 30 min/d of physical activities at least at moderate intensity ($\geq$3 metabolic equivalents of task [METs]), and patients are sedentary when they perform less than 30 min/d of activities. Research suggests that 30 min/d of physical activities at least at moderate intensity is equivalent to taking approximately 10 000 steps per day in healthy adults.[18, 19] It is not evidence based yet that this is true also for HF patients, but in the absence of HF-specific criteria, comparing the number of steps per day with the criteria for healthy adults as proposed by Tudor-Locke and Basset[18] can give an indication about how to interpret the amount of steps that HF patients take per day. Based on these criteria, fewer than 5000 steps per day could be considered as a sedentary lifestyle; from 5000 to 10 000 step per day, as a low-somewhat physically active lifestyle; and more than 10 000 steps per day, as a physically active lifestyle.[20]

Tung et al.[21] endorsed the importance of assessing and improving daily physical activity levels in HF patients. However, for a better understanding of how healthcare providers can successfully improve physical activity in sedentary HF patients, more knowledge about related factors is necessary. Daily physical activity is related to a complex set of factors,[22] including exercise capacity and clinical factors. We hypothesize that daily physical activity may also be associated with the physical activity advice that HF patients receive from their physician.[23] In addition, the exact contribution of demographic characteristics (eg, age, gender, living situation, level of education), cardiac risk factors (eg, smoking, overweight/obesity), and psychological characteristics (eg, self-efficacy, motivation, and depression) to variance in daily physical activity in HF patients has remained elusive.

The aims of this study, therefore, were to (*a*) describe performance-based daily physical activity in stable outpatients with HF; (*b*) assess the prevalence of physical activity levels in these patients, whether physically active or sedentary; and (*c*) identify related factors of daily physical activity.

Methods

Study design

For this cross-sectional study, stable outpatients with HF were recruited between February 2010 and February 2011 from HF clinics of the University Medical Centre of Groningen and Martini Hospital, both in Groningen, the Netherlands. The study complied with the principles outlined in the Declaration of Helsinki and was approved by the medical ethics committee of the University Medical Centre of Groningen. Eligible patients were asked to participate by the researcher, during a routine visit to the HF nurse. All participants gave their written informed consent.

Study sample

The patients were screened for eligibility by an HF nurse. Inclusion criteria were (*a*) diagnosis of HF, (*b*) New York Heart Association (NYHA) class I to III, (*c*) evidence of structural underlying heart disease, (*d*) stable condition (ie, diuretics unchanged for ≥4 weeks), (*e*) age 18 years or older, (*f*) able to walk/cycle, and (*g*) able to understand and complete questionnaires in Dutch. Exclusion criteria were (*a*) life expectancy less than 1 year, (*b*) underwent or will undergo an invasive intervention (eg, percutaneous coronary intervention, coronary artery bypass graft, valvular replacement) in the last 6 months or planned within the next 3 months, (*c*) participation in another HF study, (*d*) has a pacemaker, implantable cardioverter-defibrillator, or cardiac resynchronization therapy device (noninterference with the accelerometer could not be guaranteed), (*e*) signs of ventricular tachycardia and atrial fibrillation during increased physical activity, and (*f*) recent lung embolism (<3 months before start of study).

Measurements

Demographic and clinical data

Demographic and clinical data were obtained from the participants' medical records and by interviewing the participants.

Daily physical activity

To measure daily physical activity, participants were instructed to wear an accelerometer SenseWear Pro3 Armband (BodyMedia, Inc, Pittsburgh, Pennsylvania) for 2 consecutive weekdays (48 hours). According to Rowe et al.[24] 2 days of measurement is sufficient to obtain data with a reliability above an intraclass correlation coefficient (ICC) of 0.80. The SenseWear is a 2-axis accelerometer and has to be worn on the right upper arm, over the triceps muscle. The researcher attached the device on the arm of the participant. The SenseWear is a user-friendly device because it is easy to attach/detach, leads to minimal discomfort, and has no interference in activity. There is no display on the device; thus the participants received no direct feedback on their physical activity. After the wearing period, the participants returned the SenseWear to the researcher by mail. The researcher retrieved the data from the device with the corresponding software of BodyMedia. Although the SenseWear is not specifically validated for HF patients, no extensive problems were expected. The SenseWear has a good test-retest reliability (r = 0.87-0.94)[25] and a high ICC (0.80) with the doubly labelled water method.[26] The SenseWear has a good validity when compared with indirect calorimetry ($r = 0.86$; $P < .001$)[27] and with the doubly labelled water method ($r = 0.479$; $P < .01$).[28] A few minutes per day of nonwearing time are inevitable because of the non-water resistance of the SenseWear, for example, in case of showering. To determine the cutoff point of how much nonwearing time was allowed and still have a good representation of a complete day, the 70%-80% rule was used.[29] Sufficient wearing time was defined as wearing the accelerometer for 80% of the "wearing day"; wearing day was defined as the length of time in which at least 70% of the sample was wearing the accelerometer.[29] Patients with insufficient wearing time were excluded. A complete measurement of the SenseWear had a duration of 24 hours, which is indicated by the SenseWear as a wearing time of 100%. To standardize the values of incomplete measurements to complete 24 hours data the following formula was used: (outcome measure/percentage wearing time) x 100. Outcome measures of the SenseWear are total energy expenditure (kcal), number of steps, average METs, active energy expenditure (kcal), time spent on physical activities at least at moderate intensity (≥3 METs), and time spent on activities at sedentary-light (up to 3 METs), moderate (3-6 METs),

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and vigorous (6-9 METs) intensities. Steps per day and time spent on physical activities at least at moderate intensity (≥3 METs) in minutes per day were the primary daily physical activity outcomes. For reference purposes, the primary daily physical activity outcomes were compared with the 30-minute physical activity guideline[3] and the steps criteria for healthy adults (specific HF steps criteria are lacking) as proposed by Tudor-Locke and Basset (Text Box).[18]

Text Box
Lifestyle classification when compared with:

- 30-min activity guideline[3]
  Sedentary lifestyle: <30 min/d physical activity (≥3 METs)
  Physically active lifestyle: >30 min/d physical activity (≥3 METs)

- Steps criteria for healthy adults[25]
  Sedentary lifestyle: <5000 steps/day
  Low-somewhat physically active lifestyle: 5000-10 000 steps/day
  Physically active lifestyle: >10 000 steps/day

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Psychological characteristics
Bandura's Exercise Self-Efficacy Scale (ESES) was used to assess exercise self-efficacy.[30,31] This is a valid and reliable scale for a cardiac population.[31] The ESES consists of 18 items on which subjects rate, on a 0-to-10 scale, how certain they are that they can perform regular physical activity across a range of circumstances. Total ESES (0-180) is the outcome measure; higher scores mean a higher level of exercise self-efficacy.

The Self-Regulation Questionnaire–Exercise was used to assess intrinsic motivation.[32, 33] The Self-Regulation Questionnaire–Exercise is a reliable instrument and has a good construct validity.[33] Patients rate, on a 7-point scale, to what degree 16 different reasons explain why they exercise regularly. The Relative Autonomy Index was calculated from the scores. Higher scores mean a more autonomous regulatory style.

The depression subscale of the Hospital Anxiety and Depression Scale was used to assess depression.[34, 35] This scale is a reliable and valid screening tool for depression in cardiac patients.[34, 35] The depression subscale consists of 7 items, rated on a 4-point Likert scale. Higher scores indicate more depressive symptoms. A score of 8 points or higher is a consensus cutoff score for indication of a psychiatric condition.

Physical activity advice
Participants were asked by questionnaire whether they received any physical activity advice from their cardiologist and, if any, what comprised that advice.

Data analysis
Descriptive statistics were used to characterize the participants and their daily physical activity outcomes. Spearman ranks correlation coefficients of daily physical activity outcomes were calculated. The scores on the primary daily physical activity outcomes were compared with the 30-minute guideline[3] and the steps criteria.[18] To identify determinants of daily physical activity, we used multiple linear regression analyses for the total group. Variables that showed significant differences in daily physical activity between categories (dichotomous/ordinal variables) and variables that were significantly correlated to daily physical activity (continuous variables) were entered into the analyses as independent variables. In secondary analyses, linear regression analyses were also performed separately for patients with NYHA I to II and NYHA III. All analyses were performed in the statistical programming language and environment R and SPSS (17.0); p-values of $<.05$ were considered significant.

Results
Study sample characteristics
In total, 89 (82%) of the 109 approached stable outpatients with HF (all whites) agreed to participate in the study. Twenty patients (60% men, 40% women) refused to participate for a variety of reasons (eg, no time, not interested, too much of a burden). Twenty-one patients (44% men, mean age of 59 $\pm$ 13 years, 94% NYHA I-II) had to be excluded because they had insufficient SenseWear data. The excluded patients differed significantly from the patients who had sufficient SenseWear data only in NYHA classification ($X^2 = 6.6$; $P < .05$). In total, data from 68 HF patients (71% men, mean age of 62 $\pm$ 14 years, 60% NYHA I-II , left ventricular ejection fraction [EF] of 35% $\pm$ 15%) could be analyzed. Most (61%) of those 68 participants reported receiving physical activity advice from their cardiologist, but most of the advice was limited to the remark that physical activity is good or desirable (89%). Four patients (11%) reported that they received advice that included a recommendation about type, duration, intensity, or frequency of physical activity. Other patient characteristics are presented in Table 1.

Table 1 Characteristics of participants (N = 68)

Demographic characteristics	
Age, y	62 ±14
Gender	
Men	48 (71)
Women	20 (29)
Level of education	
Low-moderate [a]	37 (55)
Moderate-high [b]	30 (45)
Living alone	14 (21)
Cardiac risk factors	
BMI, kg/m2	27.6 ± 4.8
Overweight (BMI 25-30 kg/m2)	29 (43)
Obesity (BMI >30 kg/m2)	18 (27)
Smoking (yes)	7 (10)
Disease-specific characteristics	
NYHA class	
I-II	41 (60)
III	27 (40)
EF, %	35 ± 15
≤40%	44 (66.7)
>40%	22 (33.3)
Diabetes	14 (21)
COPD	10 (15)
Psychological characteristics	
Self-efficacy (ESES)	92 ± 37
Motivation (RAI)	8 ± 5
Depression (HADS)	5 (2-8)

Data are presented as means ± SD or n (%), except for depression, which is presented as median (IQR) because of non-normality.
Abbreviations: BMI, body mass index; COPD, chronic obstructive pulmonary disease; EF, ejection fraction; ESES, Exercise Self-Efficacy Scale; HADS, Hospital Anxiety and Depression Scale; IQR, interquartile range; NYHA, New York Heart Association; RAI, Relative Autonomy Index.
a Low-moderate education: no education, primary education, lower/preparatory applied education, or middle level general continued education.
b Moderate-high education: middle-level applied education, higher general continued education/preparatory scientific education, higher applied education, or scientific education.

Performance-based description of daily physical activity

SenseWear wearing time ranged from 39 to 48 hours (mean, 47 ± 2 hours). The median number of steps was 4950 (interquartile range [IQR], 2961-7934) and the median time spent on activities at least at moderate intensity was 43 min/d (IQR, 13-70) (Table 2). The ICC between the measurements of steps per day was 0.728 and between the measurements of time spent on activities at least at moderate intensity the ICC was 0.705. The association between steps per day and time spent on physical activities at least at moderate intensity in minutes per day is illustrated in the Figure (Spearman $\rho = 0.77$; $P < .01$). The Figure shows the wide range in steps per day (464-15300) and in time spent on physical activities at least at moderate intensity in minutes per day (0-255). In addition, there was also a wide range of daily physical activity across the different NYHA classes. A more detailed description of daily physical activity is presented in Table 2 for the total group and for patients with NYHA I to II and NYHA III separately. All daily physical activity outcomes were significantly correlated to each other (Spearman $\rho = 0.28$-0.99). Patients with NYHA III took significantly fewer steps per day than did patients with NYHA I to II ($U = 267.0$; $P < .001$) and spent significantly less time on physical activities at least at moderate intensity than did patients with NYHA I to II ($U = 276.5$; $P < .01$).

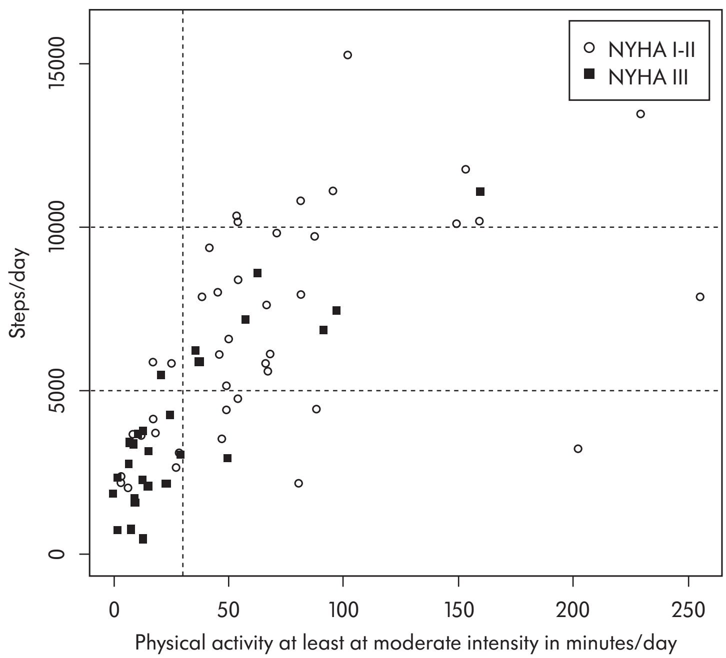

Figure 1 Physical activity at least at moderate intensity in minutes per day. NYHA indicates New York Heart Assocoation

Daily physical activity compared with guidelines

Table 2 shows also the primary daily physical activity outcomes in relation to the steps criteria[18]

Table 2 Description of daily physical activity

Outcome	Total (N = 68)	NYHA I-II (N = 41)	NYHA III (N = 27)
Number of steps per day			
Median (IQR) Mean ± SD	4950 (2961-7934) 5619 ± 3384	6113 (3699-9767) 6762 ± 3366	3150 (2069-5880) 3882 ± 2624
<5000, % of N (95% CI)	50 (38-62)	37 (22-52)	70 (53-87)
5000-10 000 , % of N (95% CI)	35 (24-46)	41 (26-56)	26 (10-46)
>10 000 , % of N (95% CI)	15 (7-23)	22 (9-35)	4 (-4-12)
Physical activity at least at moderate intensity (≥3 METs)			
Median (IQR), min/d	43 (13-70)	54 (28-84)	15 (9-38)
Mean ± SD, min/d	54 ± 55	70 ± 60	31 ± 37
< 30 minutes/day, % of N (95% CI)	44 (32-56)	27 (14-41)	70 (53-87)
> 30 minutes/day, % of N (95% CI)	56 (44-68)	73 (59-87)	30 (13-47)
Sedentary-light physical activity (0-3 METs)			
Median (IQR) Minutes per day Hours per day	 1398 (1371-1427) 23.3 (22.9-23.8)	 1387 (1357-1413) 23.1 (22.6-23.6)	 1425 (1404-1432) 23.8 (23.4-23.9)
Mean (± SD) Minutes per day Hours per day	 1387 ± 55 23.1 ± 0.9	 1371 ± 59 22.9 ± 1.0	 1410 ± 37 23.5 ± 0.6
Moderate physical activity (3-6 METs)			
Median (IQR), mind/d Mean ± SD, min/d	43 (13-70) 53 ± 54	54 (28-84) 69 ± 58	15 (9-38) 30 ± 36
Vigorous physical activity (6-9 METs)			
Median (IQR), min/d Mean ± SD, min/d	0 (0-1) 1 ± 2	0 (0-1) 1 ± 3	0 (0-0) 0 ± 1
Average METs			
Median (IQR) Mean ± SD	1.2 (1.0-1.3) 1.2 ± 0.2	1.3 (1.1-1.4) 1.3 ± 0.2	1.1 (1.0-1.2) 1.1 ± 0.2
Total energy expenditure			
Median (IQR), kcal/d Mean ± SD, kcal/d	2390 (1954-2743) 2415 ± 531	2531 (2203-2878) 2601 ± 519	2042 (1843-2390) 2134 ± 419
Active energy expenditure (at ≥ 3METs)			
Median (IQR), kcal/d Mean ± SD, kcal/d	233 (67-368) 284 ± 302	292 (142-399) 376 ± 338	76 (44-155) 143 ± 159

Data are presented as median and IQR because of nonnormality, but mean and SD are presented as well.

Abbreviations: CI, confidence interval; IQR, interquartile range; MET, metabolic equivalent of task; NYHA, New York Heart Association.

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and the 30-minute guideline[3] for the total group and for patients with NYHA I to II and NYHA III separately (Table 2). Fifty percent of all participants took fewer than 5000 steps per day and 44% was less than 30 min/d physically active at least at moderate intensity. Fifteen percent of all participants took more than 10 000 steps/day and 56% was more than 30 min/d physically active at least at moderate intensity.

Related factors of daily physical activity (steps per day)

Steps per day differed significantly between patients with NYHA I to II (median, 6113) and patients with NYHA III (median, 3150) (U = 267.0; P < .001). There was also a significant difference in steps per day between patients with an EF of 40% or lower (median, 5854) and patients with an EF greater than 40% (median, 3246) (U = 328.0; P < .05). There was no significant difference in steps per day between men and women (U = 416.0; P = 0.389). Steps per day was significantly correlated only to age (Spearman ρ = -0.43) and self-efficacy (Spearman ρ = 0.40) but not to other characteristics. A linear regression model using NYHA classification, EF, age, and self-efficacy explained 42% of the variance in steps per day (F = 8.69; P < .001). Self-efficacy and NYHA classification contributed significantly to the model (Table 3).

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Table 3 Coefficients of overall regression model - Dependent variable: steps per day

					95% CI	
	B	**SE**	***t***	***P***	**Lower Bound**	**Upper Bound**
NYHA	-1478.62	398.66	-3.71	.001	-2280.18	-677.06
EF(1= ≤40; 2= >40)	-505.10	855.52	-.59	.558	-2225.24	1215.04
Age (in years)	-54.05	29.27	-1.85	.071	-112.89	4.79
Self-efficacy (0-180)	33.20	11.49	2.89	.006	10.10	56.30

Abbreviations: CI, confidence interval; EF, ejection fraction; NYHA, New York Heart Association.

Stratification by NYHA classification showed that in patients with NYHA I to II, self-efficacy remains the most important factor in explaining variance in steps per day. In patients with NYHA III, the most important factors were self-efficacy and physical activity advice patients received from their cardiologist (data not shown).

Related factors of daily physical activity (time spent on physical activities at least at moderate intensity per day)

Also time spent on physical activities at least at moderate intensity (minutes per day) differed significantly between patients with NYHA I to II (median, 54 min/d) and patients with NYHA III (median, 15 min/d) (U = 276.5; P < .01). There was also a difference between patients with an EF of 40% or lower (median, 257 min/d) and patients with an EF of greater than 40% (median, 78 min/d) (U = 331.5; P < .05), but not between men and women (U = 458.0; P = .767). Time spent on physical activities at least at moderate intensity was significantly correlated only to age (Spearman ρ = -0.28), body mass index (Spearman ρ = -0.25), and self-efficacy (Spearman ρ = 0.28) but not to other characteristics. A linear regression model using NYHA classification, EF, age, body mass index, and self-efficacy explained 19% of the variance in time spent on physical activities at least at moderate intensity (minutes per day) but was not significant (F = 2.26; P = .064). New York Heart Association classification contributed significantly to the model, but the other variables were not significant (Table 4).

Stratification by NYHA classification showed that self-efficacy was also the most important variable in explaining the variance in time spent on physical activities at least at moderate intensity (minutes per day) in patients with NYHA III (data not shown).

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Table 4 Coefficients overall regression model - Dependent variable: time spent on physical activities at moderateintensity or higher

					95% CI	
	B	SE	t	*P*	Lower Bound	Upper Bound
NYHA	-20.80	7.69	-2.70	.010	-36.27	-5.33
EF (1= ≤40; 2= >40)	-4.20	16.52	-0.25	.800	-37.43	29.03
Age (in years)	-0.18	0.57	-0.32	.748	-1.32	0.95
BMI (kg/m2)	-2.05	1.52	-1.35	.183	-5.10	1.00
Self-efficacy (0-180)	0.19	0.22	0.85	.401	-0.26	0.64

Abbreviations: BMI, body mass index; CI, confidence interval; EF, ejection fraction; NYHA, New York Heart Association

Discussion

From the performance-based description of daily physical activity in stable outpatients with HF it can be concluded that approximately half of the patients have a sedentary lifestyle. Our results indicate that NYHA classification and self-efficacy are the most important factors related to daily physical activity in HF patients; higher NYHA classification and lower self-efficacy are associated with less daily physical activity.

Physical activity guidelines are necessary for interpreting daily physical activity behaviour. Based on the 30-minute activity guideline,[3, 11-13] 44% of the HF patients in our study can be considered as having a sedentary lifestyle because they performed less than 30 minutes of moderate- to vigorous-intensity physical activities per day. The number of steps per day can give an indication about patients' lifestyle as well. Fifty percent took fewer than 5000 steps per day. Compared with criteria for healthy adults, these patients could therefore be considered as sedentary. However, we have to keep in mind that these steps criteria are based on normative data in healthy adults and might not be suitable for all HF patients.[19, 20] Although for some HF patients it might be impossible to achieve more than 10 000 steps per day (which is recommended for a healthy lifestyle for healthy adults), we showed that this is not necessarily impossible for all HF patients; 15% took more than 10 000 steps per day. However, specific step criteria for HF patients are lacking because normative data of HF patients are limited and the levels of physical activity varies considerably between patients.[19] Further research is necessary to adjust the original steps criteria for HF patients.

In general, patients with a chronic disease are less physically active compared to healthy adults.[19] Normative data for healthy adults range from 2000 to 9000 steps per day, and for special populations, from 1200 to 8800 steps per day.[19] The mean number of steps per day in the stable outpatients with HF in the present study was 5619 $\pm$ 3384 and ranges from 464 to 15 300. The average time spent on moderate-intensity physical activities was comparable with healthy (older) adults. Hamer et al.[36] showed that 54.4% of healthy adults with a mean age of 66 $\pm$ 6 years were at least 30 min/d physically active at moderate intensity, compared with 56% of the HF patients in the present study. The time that stable outpatients with HF spent on activities at moderate intensity is also comparable with that of patients with congenital heart disease (mean $\pm$ SD, 54 $\pm$ 55 vs 59 $\pm$ 40 min/d, respectively).[37] However, a smaller proportion of HF patients met the recommended level of physical activity (56%) than did patients with congenital heart disease (76%) .[37] Only a few other studies reported using more objective daily physical activity measures in HF patients. [9, 14, 15] Those studies reported a low level of daily physical activity as well, with a mean number of steps per day comparable with our findings: approximately 3000 to 5000.[9, 15] One study reported a higher level of daily physical activity (7257 $\pm$ 3226 steps per day).[14] However, the authors found that the participants felt encouraged to perform more physical activity when they wore an accelerometer, which implies that the actual daily physical activity level was lower. The issue of encouragement is less relevant in our study because the accelerometer did not provide any direct feedback to the participants.

The complexity of daily physical activity is also illustrated by the great variance in daily physical activity between our patients, even within NYHA classes.[22] New York Heart Association classification was one of the most important determinants in explaining the variance in daily physical activity. Heart failure patients with a higher NYHA classification were significantly less physically active than those with a lower NYHA classification, which is consistent with the literature.[14] More strikingly is that self-efficacy, defined as belief in one's own competences, is also related to performance-based daily physical activity in HF patients. Patients with a higher self-efficacy were more physically active in daily life than were patients with a lower self-efficacy. Regardless of NYHA classification, self-efficacy seemed to be the most important variable in explaining the variance in daily physical activity. This is consistent with the findings of Tierney et al,[38] who concluded that self-efficacy is one of the factors that influence physical activity in HF patients. Other research has shown that self-efficacy is a strong predictor of adherence of HF patients to physical activity recommendations.[39]

In our study, 61% reported that they received physical activity advice from their cardiologist. However, the advice did not affect a patient's daily physical activity. It is likely that the cardiologists did not give the specific daily physical activity advice that is needed for behavioral change, which reinforces the findings of another study.[16] Most advices were limited to remarks such as "Physical activity is good" or "Just do it!" but to have an effect, advice should be structured, specific, and concrete.[23] Perhaps, other healthcare providers in the HF team (eg, advanced practice nurses/ HF nurses) are more suitable to deliver such advice.[40]

Besides the small sample size and the cross-sectional study design, some additional characteristics of this study should be noted when interpreting the results. Compared with self-report measurements of daily physical activity, progress has been made by measuring daily physical activity on a performance-based way with accelerometry. However, we measured only 2 weekdays. Several studies recommend measuring daily physical activity for 3 to 7 days to obtain an accurate view of actual daily physical activity (eg, Scheers et al[41]). However, none of those studies included HF patients. We measured 2 weekdays, because research suggests that fewer days of data are sufficient in measuring daily physical activity in older adults, due to less variability between the days,[24, 42] which is probably also true for our study population. We showed, indeed, in the present study that the reliability between the 2 measured days was high, with ICCs of 0.728 and 0.705 for steps per day and time spent on moderate-intensity physical activities, respectively. However, there is no consensus yet on the number of measurement days needed to accurately measure actual daily physical activity behavior, especially in patient populations.[43] Furthermore, the SenseWear Pro 3 armband was not validated specifically for HF patients. More research is necessary to confirm our assumption that the validity and reliability estimates of the SenseWear Pro 3 armband in healthy (older) adults are not very different in HF patients. Another characteristic that should be taken into account is that 21 (of 89) patients had to be excluded because of insufficient accelerometer data. Most of those excluded patients (94%) were classified as NYHA I to II, possibly introducing bias. Failure to obtain sufficient accelerometer data can be caused by several (known and unknown) reasons, for example, mechanical flaws or early removal of the accelerometer because of (skin) irritations. For future research, we recommend assessing adherence to wearing instructions and reasons for lack of adherence.

Conclusions

The variance in daily physical activity in stable outpatients with HF is considerable. Approximately half of the patients have a sedentary lifestyle. Higher NYHA classification and lower self-efficacy are associated with less daily physical activity. We suggest that advanced practice nurses/HF nurses can play an important role in promoting daily physical activity in sedentary HF patients by delivering structured, concrete and specific advice, thereby taking into account the role of self-efficacy. More research is needed to optimize daily physical activity guidelines and steps criteria for HF patients and to further explore associated variables, preferably with a larger sample size and a longitudinal study design. Finally, these findings contribute to the understanding of daily physical activity behavior of HF patients and can help healthcare providers to promote daily physical activity in sedentary HF patients.

What's new and important?

- This study confirms the suggestion of low levels of daily physical activity in HF patients by means of performance-based measurements of daily physical activity. Performance-based measurements, in contrast to questionnaires, give a detailed insight into daily physical activity in real-time. It offers specific information about the diversity, duration, and intensity of daily physical activity throughout the day. The measurements showed approximately half of the participating HF patients can be classified as sedentary.
- Self-efficacy and NYHA classification are the most important factors related to daily physical activity in HF patients; higher NYHA classification and lower self-efficacy are associated with less daily physical activity.
- The findings of the present study contribute to the understanding of daily physical activity behavior of HF patients and can help healthcare providers to promote daily physical activity in sedentary HF patients.

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Quantifying daily physical activity and determinants in sedentary patients with Parkinson's disease

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Abstract

Background

Although physical activity is beneficial for Parkinson's disease (PD) patients, many do not meet the recommended levels. The range of physical activity among sedentary PD patients is unknown, as are factors that determine this variability. Hence, we aimed to (1) assess daily physical activity in self-identified sedentary PD patients; (2) compare this with criteria of a daily physical activity guideline; and (3) identify determinants of daily physical activity.

Methods

Daily physical activity of 586 self-identified sedentary PD patients was measured with a tri-axial accelerometer for seven consecutive days. Physical fitness and demographic, disease-specific, and psychological characteristics were assessed. Daily physical activity was compared with the 30-min activity guideline. A linear mixed-effects model was estimated to identify determinants of daily physical activity.

Results

Accelerometer data of 467 patients who fulfilled all criteria revealed that >98% of their day was spent on sedentary to light-intensity activities. Eighty-two percent of the participants were 'physically inactive' (0 days/week of 30-min activity); 17% were 'semi-active' (1-4 days/week of 30-min activity). Age, gender, physical fitness, and scores on the Unified Parkinson's Disease Rating Scale explained 69% of the variability in daily physical activity.

Conclusions

Performance-based measurements confirmed that most self-identified sedentary PD patients are 'physically inactive'. However, the variance in daily physical activity across subjects was considerable. Higher age, being female, and lower physical capacity were the most important determinants of reduced daily physical activity. Future therapeutic interventions should aim to improve daily physical activity in these high-risk patients, focusing specifically on modifiable risk factors.

Keywords

Physical activity; Parkinson's disease; Physical fitness; Health behavior

Introduction

Physical activity, which includes exercise as well as daily physical activities,[1] is important for patients with Parkinson's disease (PD). Although physical activity will not cure the disease, it may positively affect functional capacity, physical fitness, health, and several dimensions of quality of life.[2,3]

Recommendations state that PD patients should perform at least 30 min of physical activity (≥ moderate intensity) per day (in bouts of minimal 10 min). This should be done for at least five days per week.[4] Research suggests that many PD patients do not meet this recommendation.[2,5,6] However, it is not clear how far the actual daily physical activity of patients is below the recommended level, or what the range and variability in physical activity is across patients. Therefore, daily physical activity should be quantified with an accelerometer. Compared to questionnaires, such performance-based measurements can provide more accurate and detailed information about the diversity, duration, and intensity of physical activities during the day. In addition, it is unknown which factors determine differences in daily physical activity across patients. This is important to know, because it could have implications for the way physical activity levels can be enhanced. A number of related factors have been suggested in the literature to account for differences, including disease-related features,[5,6] demographics, psychological characteristics and physical fitness.[5,7,8] However, it remains unknown how these factors specifically contribute to the variability in daily physical activity among PD patients who do not meet the recommended level of physical activity.

The primary aim of this study was to produce for the first time a performance-based description of daily physical activity in self-identified sedentary PD patients. Second, by comparing these results with criteria of the daily physical activity guideline,[4] we examined whether these patients were really 'physically inactive' (in the sense of failing to meet the recommended level of physical activity once a week) or 'semi-active' (in the sense of meeting the recommended level of physical activity one to four days per week).[9] Third, we aimed to identify determinants of daily physical activity in these patients.

Methods

Study design

All subjects in this observational study are participants in the ParkFit study, a randomized controlled trial that examined the effects of a multifaceted behavioral program on physical activity behavior.[10] PD patients below the recommended level of daily physical activity were included in the ParkFit study. This screening was initially done with a specifically developed questionnaire. Subsequently, actual daily physical activity was quantitated with an accelerometer. The baseline data of the participants in the ParkFit study were used here. The study complied with principles outlined in the Declaration of Helsinki and was approved by the local ethics committee. All participants gave their written informed consent.

Study sample

The ParkFit trial recruited patients from 32 community hospitals in the Netherlands between September 2008 and January 2010. All of these patients had received chronic care from a neurologist. Patients were included if they were diagnosed with idiopathic PD, were rated with a Hoehn and Yahr (HY) stage ≤3,[11] and were between 40 and 75 years of age. Candidate subjects were send a questionnaire with a list of physical activities and asked to indicate which activities they performed, how often and how long during a normal week. When the total amount of reported physical activity was below the recommended levels of daily physical activity (i.e. moderate-intensity physical activity for >150 min for >3 times/week or vigorous-intensity physical activity for >60 min for >3 times/week [12]), patients were included. Included PD patients are referred to throughout this study as being 'self-identified sedentary' to make it clear that their initial status was determined by perceived daily physical activity, not objectively measured activity. Exclusion criteria concerned marked cognitive impairment (Mini-Mental State Examination [MMSE] <24),[13] unability to complete Dutch questionnaires, severe comorbidities interfering with daily functioning, receiving daily institutionalized care, and previously deep brain surgery.

Measurements

Demographic and disease-specific characteristics

Demographic and disease-specific characteristics were assessed with self-report questionnaires and by trained assessors. The modified HY scale,[11] and the motor part of the Unified Parkinson's Disease Rating Scale (UPDRS)[14] were used to assess the severity of the disease. Cognition was measured with the MMSE.[13]

Daily physical activity

Approximately within 6 weeks after inclusion, participants received a tri-axial accelerometer for movement registration (TracmorD, Philips New Wellness Solutions, Lifestyle Incubator, The Netherlands) to measure daily physical activity on a performance-based way. This small device can be worn as a necklace, attached to a belt, or in a pocket. It converts activity counts via algorithms into energy expenditure in kcal per minute. It is a valid device for predicting energy expenditure in daily life, with correlations with the doubly labeled water technique ranging from .54 to .91.[15,16] Although the accelerometer was not specifically validated for PD patients, no extensive problems with validity in this specific population were expected. No unambiguous evidence exists to indicate that patients expend more energy than healthy subjects to achieve the same movements, or that patients' resting energy is elevated.[17,18]

Several literature-based decisions were made with regard to preprocessing the accelerometer data.[19] Patients were asked to wear the accelerometer every day for a period of two weeks, a 'day' being 24 h. 'Non-wearing time' was defined as a period of at least 60 consecutive minutes of zero's, with a maximum of 2 min larger than 0.2 kcal.[20] Subtracting non-wearing time from 24-h resulted in the 'wearing time'. To determine the minimal wearing time per day acceptable for a valid measurement, we used the '70/80' rule.[19] A measurement was deemed valid if the patient wore the accelerometer for at least 80% of the 'wearing day'. 'Wearing day' was defined as the length of time in which at least 70% of the subject sample was wearing the accelerometer. Seven consecutive days were included for data analysis [21], and to minimize the risk of any biasing effect from the novelty of wearing an accelerometer, these concerned only the last seven consecutive valid days.[21,22]

Daily physical activity was expressed as mean total energy expenditure per day (in kcal). This consisted of sedentary to light-intensity activities (0-3.5 kcal/min), moderate-intensity activities (3.5-7 kcal/min), and vigorous-intensity activities (>7 kcal/min) per day.[23]

Psychological characteristics

Depression and generic anxiety were measured with the Hospital Anxiety and Depression Scale (HADS).[24] The scale consists of two subscales (depression and anxiety), which have seven items each. Scores on the subscales range from 0 to 21; higher scores indicate more symptoms.

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The Self-Efficacy for Exercise Scale (SEE)[25] was used to assess their self-efficacy toward physical activity. The SEE consists of nine items that rate the degree of confidence in performing regular physical activity across a range of circumstances (range: 0-10). A higher score indicates a higher level of exercise self-efficacy.

Physical fitness

Physical fitness was measured with the 6-min walk test (6-MWT).[26] This submaximal test measures the distance (in meters) a patient is able to walk for a period of 6 min.

Data analysis

Descriptive statistics were used to characterize the participants and their daily physical activity outcomes. To calculate prevalence rates for physically active, semi-active and physically inactive patients,[4,9] we collected data on the patients' daily physical activity. The activity had to be (1) performed for at least 10 consecutive minutes, with allowable interruptions of maximally 2 min;[19] and (2) either moderate-intensity (3.5-7 kcal/min) or vigorous-intensity (> 7 kcal/min).[23] Patients were classified as 'physically active' if they were physically active for a minimum of 30 min/day (in bouts of ≥ 10 min), if the intensity of the activity was moderate or vigorous, and if they performed this activity for a minimum of 5 days/week. Patients were classified as 'semi-active' if they were moderately to vigorously active (30 min/day) for 1-4 days/week, and as 'physically inactive' if they were active for zero days/week. For exploratory reasons, we calculated prevalence rates based on the total number of minutes of moderate- to vigorous-intensity activities per day for 'physically active', 'semi-active' and 'physically inactive' patients. Average bout-length was assessed as well.

The first step for identifying determinants of daily physical activity was to calculate correlations (Spearman's rho) between mean total energy expenditure and demographics, disease-specific characteristics, physical fitness and psychological characteristics. The second step was to analyze differences in mean total energy expenditure between men and women, HY stages, and education levels by using Mann-Whitney/Kruskall Wallis tests. The final step was to fit a linear mixed-effects model by using maximum likelihood. All analyses were performed in the statistical programming language R and SPSS (17.0); p-values of <0.05 were considered significant.

Results

Study sample

In total 586 PD patients were randomized into the ParkFit trial.[10] Of these, 119 patients (20%) were excluded from the present study based on accelerometry-data preprocess decisions (see Methods). In total, 467 patients (80%) had valid accelerometry measurements (≥659 min/day) on at least seven consecutive days. There were no significant differences in age (Mann-Whitney U = 26388; p = .40); gender (Chi^2 = 1.44; p = .23); body mass index (BMI) (Mann-Whitney U = 27292; p = .76); HY stage (Chi^2 = 1.82; p = .77); disease duration (Mann-Whitney U = 27186; p = .72); daily Levodopa equivalent dose (Mann-Whitney U = 26854; p = .80); depression (HADS) (Mann-Whitney U = 25797; p = .37); self-efficacy (t = -1.10; p = .27); cognition (MMSE) (Mann-Whitney U = 27756; p = .99); or education (Chi^2 = 0.02; p = .92) between patients with insufficient (<7 valid days) and sufficient (≥7 valid days) accelerometer data. Patient characteristics of the study sample (N = 467) are presented in Table 1.

Description of performance-based daily physical activity

The median (IQR) time PD patients wore the accelerometer was 997 (234) min/day (16.6 h/day). The median (IQR) of the mean total energy expenditure per day was 463.8 kcal (271.7).

Table 1 Patient characteristics (*N* = 467)

Demographic characteristics		
Age (years)	Median (IQR) Mean (SD)	67.0 (10.0) 65.7 (7.4)
Gender		
Men	Number (%)	310 (66%)
Women	Number (%)	157 (34%)
BMI	Median (IQR) Mean (SD)	27.1 (5.1) 27.6 (4.3)
Overweight (BMI 25-30)	Number (%)	228 (49%)
Obesity (BMI >30)	Number (%)	108 (23%)
Spouse		
Yes	Number (%)	399 (86%)
No	Number (%)	67 (14%)
Education		
Low	Number (%)	272 (58%)
High	Number (%)	195 (42%)
Disease specific characteristics		
Time since diagnosis (months)	Median (IQR) Mean (SD)	44.0 (67.0) 61.8 (52.6)
Hoehn & Yahr stage		
1	Number (%)	8 (2%)
1.5	Number (%)	14 (3%)
2	Number (%)	350 (75%)
2.5	Number (%)	69 (15%)
3	Number (%)	26 (6%)
UPDRS III (0-108)	Median (IQR) Mean (SD)	32 (13) 32.9 (10.5)
Daily Levodopa equivalent dose (mg)	Median (IQR) Mean (SD)	417.9 (402.0) 480.0 (389.7)
Psychological characteristics		
Cognition (MMSE 0-30)	Median (IQR) Mean (SD)	28.0 (2.0) 28.1 (1.7)
Anxiety (HADS 0-21)	Median (IQR) Mean (SD)	5.0 (4.0) 5.3 (3.4)
Depression (HADS 0-21)	Median (IQR) Mean (SD)	4.0 (5.0) 4.8 (3.6)
Self-efficacy (SEE 0-10) (N = 168)	Median (IQR) Mean (SD)	5.4 (2.2) 5.4 (1.5)
Physical fitness		
6-MWT (in meters)	Median (IQR) Mean (SD)	400.0 (100.0) 394.6 (85.2)

Continuous variables were not normally distributed, except for self-efficacy.
BMI, Body Mass Index; HADS, Hospital Anxiety and Depression Scale; IQR, interquartile range, MMSE=Mini-Mental State Examination; SD, standard deviation; SEE, Self-Efficacy for Exercise Scale; UPDRS-III, Unified Parkinson's Disease Rating Scale, motor part; 6-MWT, 6 Minute walk test.

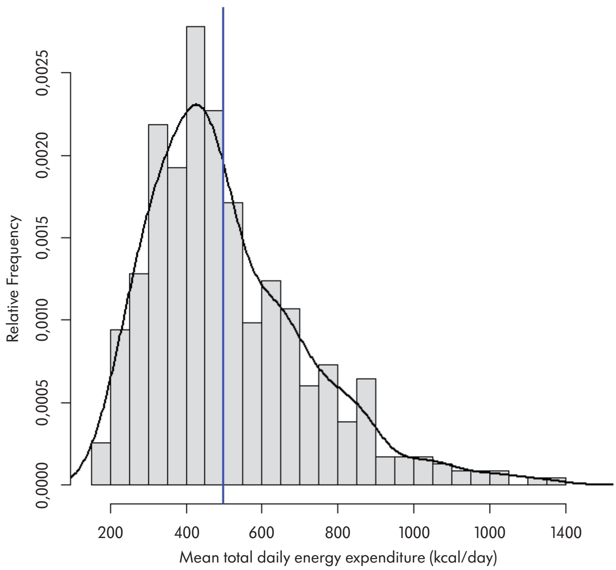

Figure 1 Distribution of mean total daily energy expenditure in kcal/day (N = 467), with density estimation for total population (median = 463.8 kcal/day, blue vertical line)

Fig. 1 presents a histogram of the distribution of the mean total energy expenditure from the study sample as well as the estimated density for the total population. This figure shows a relatively large variance in daily physical activity within the sample of self-identified sedentary patients.

Mean total energy expenditure was categorized according to the intensity of physical activity: sedentary to light, moderate, and vigorous intensity (Table 2). The median time spent on physical activities at a minimum of moderate intensity was approximately 12 min/day (≈1% of measured time).

With regard to moderate- to vigorous-intensity physical activities, the median of the average bout length was 1.6 min. The median of the maximum bout length was 6 min. Sixty percent of the participants failed to achieve an activity session of at least 10 min.

Actual daily physical activity compared to the physical activity guideline

Eighty-two percent of the participants were classified as physically inactive, and 17.3% as semi-active (Table 2). Prevalence rates differed when it was based on the total number of minutes of moderate- to vigorous-intensity activity, rather than on the recommended 10-min bouts of

Table 2 Distribution of daily physical activities and classification according to physical activity guideline (N = 467)

A. Distribution of daily physical activities[e]				
		Sedentary to light-intensity activities	**Moderate-intensity activities**	**Vigorous-intensity activities**
Energy expenditure (kcal/day)	Median (IQR) Mean (SD)	385.9 (168.2) 414.7 (147.5)	46.2 (97.5) 68.0 (76.5)	2.1 (18.4) 27.5 (63.8)
Time spent (min/day)	Median (IQR) Mean (SD)	978.6 (248.9) 1026.0 (172.0)	10.7 (20.0) 14.6 (15.9)	1.4 (2.3) 3.2 (7.2)
Percentage of day	Median (IQR) Mean (SD)	99.0% (2.5%) 98.3% (2.1%)	0.9% (2.0%) 1.4% (1.6%)	0.02% (0.2%) 0.3% (0.7%)

B. Classification according to the physical activity guideline[f]				
Physical activity at ≥ moderate intensity, accumulating..		**Physically inactive[a]**	**Semi-active[b]**	**Physically-active[c]**
..10-min bouts	N(%)	383 (82%)	81 (17.3%)	3 (0.6%)[d]
..every minute	N(%)	250 (53.5%)	148 (31.7%)	69 (14.8%)

IQR, Interquartile range; SD, standard deviation; kcal, kilocalories.
[a]Minimum of 30 min of moderate- to vigorous-intensity physical activity for zero days.
[b]Minimum of 30 min of moderate- to vigorous-intensity physical activity for 1-4 days.
[c]Minimum of 30 min of moderate- to vigorous-intensity physical activity for 5 or more days.
[d]Recommended level of physical activity.[4]
[e]Median (IQR) measured time= 997 (234) minutes/day (16.6 h/day).
[f]Thirty minutes/day physically active at ≥ moderate intensity for ≥5 days/week.[4]

activity: 53.5% of the patients were categorized as physically inactive, 31.7% as semi-active, and 14.8% as physically active.

Determinants of daily physical activity

Age (Spearman's rho = -.34, p < .001), BMI (Spearman's rho = -.11, p = .019) and the motor part of the UPDRS (Spearman's rho = -.26, p < .001) were negatively correlated to mean total energy expenditure. The MMSE (Spearman's rho = .12, p = .007) and distance on the 6-MWT (Spearman's rho = .38, p < .001) were positively correlated to mean total energy expenditure. There was no significant correlation between mean total energy expenditure and time since diagnosis (Spearman's rho = -.03, p = .53), daily levodopa equivalent dose (Spearman's rho = .07, p = .14), anxiety (Spearman's rho = .08, p = .09, depression (Spearman's rho = -.01, p = .87) and self-efficacy (Spearman's rho = .08, p = .26).

Men (mean [SD] 541.9 [209.7] kcal/day) were more physically active than women (mean [SD] 447.6 [198.8] kcal/day) (Mann-Whitney U = 16825.0; p < .001). Patients with a spouse (mean [SD] 524.1 [213.4] kcal/day) were more physically active than those without (mean [SD] 429.3 [174.8] kcal/day) (Mann-Whitney U = 9441.0; p < .001). Patients with more severe PD

Table 3 Linear mixed-effects model.[a]

Fixed effects						
					95% CI	
	Value	**SE**	***T***	***P* value**	**Lower**	**Upper**
Constant	868.43	119.45	7.27	<.001	634.39	1102.48
Age (years)	-6.70	1.30	-5.17	<.001	-9.26	-4.15
Gender (0=male; 1=female)	-60.95	20.36	-2.99	.003	-100.93	-20.98
Distance at 6-MWT (m)	.46	.13	3.61	<.001	.21	.70
UPDRS, motor function (0-108)	-2.32	.94	-2.47	.014	-4.16	-.47
Within group standard error	149.21				145.32	153.21

SE, Standard error; 6-MWT, 6-Minute walk test; UPDRS, Unified Parkinson's Disease Rating Scale.
[a] Dependent variable was mean total energy expenditure in kcal/day.

(higher HY stage) were less physically active than patients with less severe PD (lower HY stage) ($Chi^2 = 12.4$; $p = .002$).

To estimate a linear mixed-effects model for predicting mean total energy expenditure, we used variables that were significantly different in mean total energy expenditure (gender, spouse, HY) and variables that were significantly correlated to mean total energy expenditure (age, BMI, UPDRS, MMSE and distance on the 6MWT). The best model found according to minimum Akaike information criterion (AIC) had all coefficients significant, including age, gender, distance on the 6-MWT, and the motor part of the UPDRS ($R^2 = 0.69$) (Table 3).

Discussion

The present study demonstrates that daily physical activity of self-identified sedentary PD patients varies widely, but the majority of their time is associated with sedentary to light-intensity physical activities. Using a performance-based assessment of daily physical activities, we report for the first time that most self-identified sedentary PD patients (82%) can indeed be classified as physically inactive and a smaller proportion (17%) as semi-active. Higher age, being female, more motor problems, and less physical fitness were the most important determinants of reduced daily physical activity.

Variability in daily physical activity is always present to a greater or lesser extent both in healthy adults and in chronically ill patients.[27] Our results show that, even among a selected subcategory of self-identified sedentary PD patients, however, the variability in daily physical activity is still considerable. Although the majority (82%) failed to meet the daily recommended level of 30 min activity, even for one day per week, some (17%) did achieve the recommended level for one to four days per week. This suggests that even self-identified sedentary PD patients are capable of performing at least some physical activity. This is important new information for designing physical activity promotion programs for inactive PD patients. Even if these patients cannot meet the recommended level of physical activity, some activity is still considered to be better than none.[28]

The results of our study show that performing moderate-intensity activity for a minimum of 10 consecutive minutes was problematic for self-identified sedentary PD patients; the median length of their activity sessions was only 1.6 min. The majority (61%) of our participants failed to perform a single 10-min session in a week. When data were collected on each minute of activity performed at a moderate to vigorous-intensity, we found that more patients (46.5%) performed 30 min of activity per day than when data were collected on only 10-min sessions of activity (18%). Further research should clarify whether 10-min bouts (which are currently recommended) are really necessary to produce health effects in PD patients.

The present study showed that self-identified sedentary PD patients spent the largest part of their day engaging in sedentary to light-intensity physical activities (98.3%). This is in line with another study showing that patients with advanced PD were sedentary (lying/sitting) for 76.7% of the time.[29] Also healthy adults and older people have been shown to spend most of their day on sedentary to light-intensity physical activities.[30] The pattern of sedentary behavior in PD patients might be different, however, compared to that of healthy adults.[29] The participants in the present study spent only 1% of the measured time on activities performed at a moderate to vigorous-intensity, which translates to approximately 12 min per day. By contrast, healthy adults perform moderate-intensity activities for 34 min per day, on average.[30]

Daily physical activity in self-identified sedentary PD patients is associated with several factors. Our findings corroborate those resulting from the survey of Bauman et al. (2002), who summarized factors often associated with physical activity.[8] Higher age, higher BMI, and more motor problems were associated with less daily physical activity, as was gender (females), lacking a spouse, and severe disease. Conversely, better cognition and higher levels of physical fitness were associated with more daily physical activity. Our results showed that the variability in daily physical activity was mainly explained by age, gender, motor problems and physical fitness. The linear mixed-model showed that as age increases by one year, daily physical activity decreases by 6.7 kcal/day. Women spent 61.0 kcal/day less on daily physical activities than men. One point higher on the motor part of the UPDRS results in a decrease of 2.3 kcal/day spent on daily physical activities. An improvement of 1 m on the 6MWT results in an increase in daily physical activity of 0.5 kcal/day.

In other patient populations (e.g. heart failure patients[31]), physical fitness is also an important predictor of daily physical activity. Our findings illustrate that daily physical activity is related in part to factors that cannot be changed (age, gender), but also in part to factors that are modifiable (physical capacity such as motor problems and physical fitness). Several studies show that the physical capacity of PD patients can be improved by exercise.[32] However, more research is needed to support the suggestion that this lead to actual increase in daily physical activities, because the direction of the relationship between physical capacity and daily physical activity could not be defined based on our results.

When interpreting the present results, it should be noted that only self-identified sedentary patients were included and that 75% of the participants was classified with Hoehn and Yahr stage 2. Therefore, the results may not be representative of the total PD population and caution must be taken in generalizing the results of this study to all sedentary PD patients. In addition, approximately 65% of the self-identified sedentary patients were reluctant to participate in the ParkFit trial, possibly introducing selection bias. Since the present study used the baseline data of the ParkFit trial, daily physical activity of reluctant patients was not part of our analysis. With regard to the physical activity measurements, it should be noted that the measurements were done during 1.5 year, thereby possibly introducing a random error due to seasonal variations in weather. It should also be noted that the accelerometer was not specifically validated for PD patients. Further research should reveal the validity in this specific population, and examine whether tremor may impact the measurements.

In conclusion, self-identified sedentary PD patients spent the majority of their time being sedentary or performing light-intensity physical activities. The variability in physical activity is considerable and can be, in part, explained by age, gender, and physical capacity. Higher age, being female, having more motor problems, and being less physically fit are the most important determinants of reduced daily physical activity. Age and gender cannot be modified by experimental intervention, but physical capacity can. We suggest that future therapeutic interventions aim to improve daily physical activity in these high-risk patients by focusing, in particular, on modifiable risk factors.

Competing interests

BRB has served as an editorial board member of *Movement Disorders*, currently serves as an editorial board member of *Physiotherapy Canada*, and is Associate Editor for the *Journal of Parkinson's disease*. He received honoraria from serving on the scientific advisory board for Boehringer Ingelheim, Teva, Glaxo-Smith-Kline and Novartis and research support from the Netherlands Organization for Scientific Research (016.076.352), the Michael J Fox Foundation, the Prinses Beatrix Foundation, the Stichting Internationaal Parkinson Fonds and the Alkemade Keuls fonds. MM received grants from ZonMw, the Michael J Fox Foundation, the National Parkinson Foundation, the Dutch Parkinson's Disease Society, and the Prinses Beatrix Fonds.

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6

Longitudinal measurement of physical activity following kidney transplantation

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Abstract

The purpose of this longitudinal observational study was to (i) examine the change of daily physical activity in 28 adult kidney transplant recipients over the first 12 months following transplantation and (ii) to examine the change in metabolic characteristics and renal function. Accelerometer-based daily physical activity and metabolic- and clinical characteristics were measured at six wk (T1), three months (T2), six months (T3) and 12 months (T4) following transplantation. Linear mixed effect analyses showed an increase in steps/d (T1 = 6326 ± 2906; T4 = 7562 ± 3785; $F = 3.52$; $p = 0.02$), but one year after transplantation only 25% achieved the recommended 10 000 steps/d. There was no significant increase in minutes per day spent on moderate-to-vigorous intensity physical activity (T1 = 80.4 ± 63.6; T4 = 93.2 ± 55.1; $F = 1.71$; $p = 0.17$). Body mass index increased over time (T1 = 25.4 ± 3.2; T4 = 27.2 ± 3.8; $F = 12.62$; $p < 0.001$), mainly due to an increase in fat percentage (T1 = 30.3 ± 8.0; T4 = 34.0 ± 7.9; $F = 14.63$; $p < 0.001$). There was no significant change in renal function ($F = 0.17$; $p = 0.92$). Although the recipients increased physical activity, the majority did not meet the recommended levels of physical activity after one year. In addition to the weight gain, this may result in negative health consequences. Therefore, it is important to develop strategies to support kidney transplant recipients to comply with healthy lifestyle recommendations, including regular physical activity.

Keywords

Kidney transplantation; Motor activity; Health behavior; Adult; Longitudinal studies

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Introduction

Chronic kidney disease is a common disease worldwide with prevalence rates of 7.2% in adults (≥30 year of age) and 23.4% - 35.8% in older adults (≥64 year of age).[1] Patients with end-stage renal disease require kidney replacement therapy consisting of dialysis or kidney transplantation to survive. Although a successful transplantation reduces the mortality rate, cardiovascular disease remains the primary cause of mortality in kidney transplant recipients.[2, 3] Besides a healthy diet, sufficient physical activity reduces the risk of cardiovascular disease due to preventing obesity and improving blood pressure, lipids, insulin sensitivity, and systemic inflammation.[3-5] Physical activity, defined as any bodily movement produced by skeletal muscles that results in energy expenditure,[6] also contributes to improved physical functioning and quality of life.[7, 8] Furthermore, it has been demonstrated that physical activity is positively related to graft function.[9, 10]

There is no specific physical activity recommendation for kidney transplant recipients, but also no restrictions for performing activities.[11] In the absence of a disease specific guideline, the American College of Sports Medicine (ACSM) recommends adults with clinically significant chronic conditions to comply with the same guidelines as healthy adults as much as their abilities and conditions allow.[12, 13] Healthy adults are recommended to cumulatively perform at least 30 min per day of moderate-to-vigorous intensity physical activities (MVPA) at least five d per week in addition to routine activities of daily living.[12, 13] Another commonly employed recommendation is that healthy adults should take an average of 10 000 steps per day to maintain health.[14] Research showed that this '10 000 steps guideline' is equivalent to the ACSM recommendation.[15, 16] Thirty min walking results in approximately 3000-4000 steps; daily routine activities results in approximately 6000-7000 steps.[15] Taken together, when an individual is 30 min active in addition to the daily routine activities, a total score of 9000-11 000 steps is achieved.

Prior to transplantation, most patients with chronic kidney disease are physically inactive.[17-19] Based on previous studies it remains inconclusive whether kidney transplant recipients increase their physical activity following transplantation,[4, 5, 20] but research demonstrated that the majority of kidney transplant recipients do not meet the recommended levels of physical activity up to 12 months after transplantation.[4, 9, 20-22] However, this was based on self-reported physical activity. Utilization of self-reported physical activity contains a risk for poor reliability and validity.[23] Accelerometry is a more objective method to measure daily physical activity. Accelerometers register actual daily physical activity in a performance based way and can, therefore, offer specific information regarding diversity of daily physical activity type and intensity throughout the day, and compliance with daily physical activity guidelines. Daily physical activity can vary in time due to the natural course of events after transplantation (i.e., not prompted by a specific intervention). Therefore, it is important to measure the development of daily physical activity over a longer period of time to assess whether possible changes will last.

The first objective of this study was to examine the development of performance-based daily physical activity in adult kidney transplant recipients over the first 12 months following transplantation. The second objective was to examine the change in metabolic characteristics and renal function during the first 12 months following transplantati

Patients and Methods

Study design and study sample

For this longitudinal observational study, patients were recruited in the kidney transplantation unit at the University Medical Center of Groningen (UMCG) in Groningen, the Netherlands between October 2007 and September 2008. The study complied with the principles outlined in the Declaration of Helsinki. All participants provided written informed consent. Daily physical activity, and metabolic and clinical characteristics of the participants were assessed at six wk (T1), three months (T2), six months (T3) and 12 months (T4) after transplantation. In total, 29 adult kidney transplant recipients (≥ 18 yr of age) who received their transplant in the UMCG during the inclusion period, who were able to speak and read Dutch/English, who had no combined transplantation, no malignancies (skin malignancies excluded) and no auto-immune disease such as vasculitis or Wegeners disease, were asked to participate.

Measurements

Demographics

Demographics such as age, gender and level of education were obtained from the medical records and by interviewing the participants.

Daily physical activity

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The 2-axis accelerometer SenseWear® Pro3 Armband (BodyMedia, Inc., Pittsburgh, PA, USA) was used to measure daily physical activity. The SenseWear® has a good test-retest reliability (r = 0.87-0.94) and good validity when compared with indirect calorimetry ($r = 0.86$; $p < 0.001$).[24, 25] Participants were instructed to wear the SenseWear® for three consecutive weekdays (72 h). Measurements with insufficient wearing time (<48 h) were excluded. Steps per day and time spent on MVPA in minutes per day were the primary daily physical activity outcomes.[26, 27] MVPA consists of aerobic activities for which at least a moderate level of effort is necessary, which is expressed as ≥3 Metabolic Equivalents of Tasks [METs] (1.0 MET = energy expenditure in rest = 1.0 kcal*kg $^{-1}$ * h $^{-1}$).[26] Based on the steps-criteria as proposed by Tudor-Locke et al. (2008),

<5000 steps per day is considered as a sedentary lifestyle; from 5000 to 10 000 steps per day as a low-to-somewhat physically active lifestyle; and more than 10 000 steps per day as a physically active lifestyle.[14] Based on the ACSM guideline, a total of <30 accumulated minutes MVPA per day is considered as a sedentary lifestyle and more than 30 accumulated minutes as a physically active lifestyle.[12, 13]

Metabolic characteristics

Height and weight were measured at each time point and used to calculate body mass index (BMI) in kg/m^2. Body composition (fat percentage, fat free mass) was estimated with a single frequency bio-electrical impedance assessment (BIA, Bodystat 1500, Douglas Isle of Man, UK)at each timepoint. This is a non-invasive device which measures the entire body composition by passing a safe battery generated signal through the body and measuring the bioelectrical impedance at a fixed frequency of 50 kHz.

Clinical characteristics

The following clinical characteristics were obtained from the medical records: immunosuppresive agents, blood pressure, hypertensives, diabetes mellitus, insuline, hemoglobine (mM), erythropoiesis-stimulating agents, total cholesterol (mM), high-density lipoprotein (HDL; mM), low-density lipoprotein (LDL; mM), triglycerides (mM), serum and urine creatinine concentration (*µ*M), creatinine clearance (in mL/min), proteinuria (defined as urinary protein excretion >0.5 g/24 h), and glomerular filtration rate (GFR; mL/min). GFR was calculated with the Modification g/24 h, and glomerular filtration rate (GFR; mL/min). GFR was calculated with the Modification of Diet in Renal Disease (MDRD) equation.[28] To assess change in renal function over time, GFR was measured at T2, T3 and T4 as well.

Data analysis

Descriptive statistics were used to characterize the participants' demographics, metabolic, and clinical characteristics. Lifestyle classifications based on the primary physical activity outcomes were composed by comparing the physical activity outcomes with the steps-criteria and the ACSM guideline for each measurement (T1-T4). The development of physical activity, as well as changes in metabolic characteristics (BMI, fat percentage, fat free mass) and in renal function (GFR), over time, was tested with linear mixed effect analyses with random effects for patients and an autoregressive correlation structure for the error terms estimated by restricted maximum likelihood to avoid biased estimates of effects.[29] All analyses were performed by the statistical programming language R;[30] p-values $\leq$ 0.05 were considered significant.

Results

Study sample

Of 29 patients who were approached to participate in this study, 28 patients were enrolled. One patient did not participate because wearing the accelerometer was too burdensome. Eighteen patients had complete accelerometer measurements. Of 10 patients one, two, or three accelerometer measurements included less than 2880 min and were therefore excluded for further analyses. During the 12 months following transplantation none of the recipients had allograft loss. One patient died, but completed two measurements which fell within one or two standard deviations of the mean, and was therefore included in the analyses. Before transplantation, two patients were diagnosed with Type I Diabetes Mellitus and used Insuline glarine (Lantus, Sanofi-Aventis, Paris, France) or Insuline aspart (NovoRapid, Novo Nordisk, Bagsvaerd, Denmark). Two patients suffered from pre-transplant pulmonary disease (7.1%) and five patients from cardiovascular disease (17.9%). Before transplantation, 15 patients (53.6%) received antihypertensives, including beta blockers (21.4%), calcium antagonists (28.6%), loop diuretics (3.6%), thiazide diuretics (3.6%), alpha blockers (3.6%), and A-II antagonists or ACE inhibitors (32.1%). Nine patients (32.1%) received erythropoiesis-stimulating agents (Aranesp; Amgen B.V., Thousand Oaks, USA; NeoRecormon; Roche B.V., Woerden, The Netherlands). Following tranplantation all patients received standard immunosuppressive treatment consisted of the following: cyclosporine microemulsion (Neoral; Novartis Pharma B.V., Arnhem, The Netherlands); mycophenolate mofetil (Cellcept; Roche B.V., Woerden, The Netherlands) and prednisolone. More detailed patient characteristics of the study sample (n = 28) at T1 (6 wk after transplantation) and at T4 (12 months after transplantation) are presented in Table 1. The clinical and metabolic characteristics indicate that the sample is representative for recently transplanted kidney patients.[31, 32]

Daily physical activity

The variability in steps per day between participants was large, ranging from 801 to 11 400 at T1 and from 1756 to 15 520 at T4. There was a significant time effect in the mean number of steps per day ($F = 3.52$; $p = 0.02$). Table 2 shows the estimates of the fixed effect of time on the mean number of steps per day. The intercept value of 6314.7 represents the estimated mean number of steps at T1. The intercept for T2 is 6314.7 + 1358.2 = 7672.9, which is significanlty higher than at T1. It can be stated with 95% certainty that the mean number of steps at T2 is 165.7-2550.7 higher than at T1 ($t = 2.3$; $p = 0.026$; 95% CI 165.7-2550.7 steps). Similar, it can be stated with 95% certainty that the mean number of steps at T3 is 392.8-2454.7 higher than at T1, and the mean number of steps at T4 is 231.1-2313.2 higher than at T1 (Table 2). At T1, the observed mean (SD) number of steps per day was 6326 (2906). In total, 16% of the

Table 1 Patient characteristics at T1 (n = 28) and at T4 (n = 27)

Demographic characteristics		
Age (in yr)	54.5 (IQR 15)	55 (IQR 15)
Gender, male, n (%)	14 (50)	13 (48.1)
Level of education*		
Low, n (%)	21 (75)	21 (77.8)
High, n (%)	7 (25)	6 (22.2)
Metabolic characteristics		
BMI (kg/m^2)	25.2 (±3.2)	27.2 (±3.8)
Blood pressure		
Systolic (mmHg)	137 (±17)	144 (±17)
Diastolic (mmHg)	81 (±11)	88 (±12)
Fat (%)	29.7 (±9.4)	34.0 (±7.9)
Fat free mass (kg)	53.0 (±10.5)	52.6 (±10.2)
Cholesterol (mM)	5.55 (±1.08)	5.65 (±1.41)
HDL (mM)	1.58 (±0.44)	1.53 (±0.50)
LDL (mM)	3.30 (±1.14)	3.22 (±0.98)
Triglycerides (mM)	2.18 (±0.61)	2.43 (±1.10)
Clinical characteristics		
Transplant type		
Deceased donor, n (%)	6 (21.4)	5 (18.5)
Living related donor, n (%)	11 (39.3)	11 (40.7)
Living unrelated donor, n (%)	11 (39.3)	11 (40.7)
Dialysis type before transplantation		
None	6 (21.4)	6 (22.2)
Heamodialysis, n (%)	10 (35.7)	10 (37.0)
Heamodialysis, time in months	26 (±19)	26 (±19)
Peritoneal dialysis, n (%)	12 (42.9)	11 (40.7)
Peritoneal dialysis, time in months	25 (±26)	25.4 (±27.5)
Diabetes Mellitus		
Type 1, n (%)	2 (7.1)	2 (7.4)
Type 2, n (%)	0 (0.0)	0 (0.0)
Hemoglobine (mM)	7.4 (IQR 1.2)	8 (IQR 1.5)
Urinary creatinine excretion (μM)	9.8 (IQR 3.2)	10.60 (IQR 2.8)
Serum creatinine excretion (μM)	111.5 (IQR 34)	115.5 (IQR 28.8)
Creatinine clearance (mL/min)	60.5 (IQR 27)	65.0 (IQR 25.8)
Urinary protein excretion (g/24h)	0.3 (IQR 0.2)	0.2 (IQR 0.3)
Proteinuria (≥0.5 g/24h), n (%)	5 (19.2)	3 (12)
GFR	52.0 (IQR 34)	60.0 (IQR 18.5)
Medication		
Insuline, n (%)	2 (7.1)	2 (7.4)
Erythropoiesis-stimulating agents, n(%)	1 (3.6)	0 (0.0)
Immunosuppressives, n (%)	28 (100.0)	27 (100.0)
Neoral, n (%)	25 (89.3)	21 (77.8)

Cellcept, n (%)	28 (100.0)	25 (92.6)
Prednisolone, n (%)	27 (96.4)	25 (92.6)
Hypertensives, n (%)	21 (75.0)	21 (77.8)
Beta blockers, n (%)	14 (50.0)	15 (55.6)
Calcium antagonists, n (%)	8 (28.6)	5 (18.5)
Loop diuretics, n (%)	2 (7.1)	1 (3.7)
Thiazide diuretics, n (%)	1 (3.6)	1 (3.7)
Alpha blockers, n (%)	2 (7.1)	1 (3.7)
A-II antagonists/ACE inhibitors, n (%)	7 (25.0)	10 (37.0)

BMI, body mass index; GFR, glomerular filtration rate; HDL, high-density lipoprotein; IQR, interquartile range; LDL, low-density lipoprotein.
Data are presented as mean (± SD) or as % (N) or as median (IQR).
* Low education= no education, primary education, lower/preparatory applied education, or middle level general continued education, middle level applied education, higher general continued education/preparatory scientific education.
High education= higher applied education, or scientific education.

participants achieved the recommended level of physical activity at T1 (Table 3). At T4, the mean (SD) number of steps per day increased to 7562 (3785). Twenty-five percent of the participants achieved the recommended level of physical activity. Detailed lifestyle classifications at T1, T2, T3 and T4 based on the number of steps per day are represented in Table 3.[14]

Table 2 Estimates of fixed effects of time on steps per day according to linear mixed effect analysis (n = 28)

					95% CI	
	Estimate	SE	T	p	Lower	Upper
(Intercept)*	6314.7	656.0	9.6	<.001	5004.3	7625.1
T2	1358.2	596.9	2.3	0.026	165.7	2550.7
T3	1423.8	516.1	2.8	0.008	392.8	2454.7
T4	1272.1	521.1	2.4	0.017	231.1	2313.2

CI, confidence interval.
* 1.5 months (Intercept), three months (T2), six months (T3), 12 months (T4) after transplantation.

There was also a large variability in the amount of time spent on MVPA, ranging from 5.1 to 242.0 min/d at T1 and from 2.3 to 221.1 min/d at T4. At T1, the participants spent an average of 80.4 (SD 63.6) minutes per day at MVPA, and this increased to 93.2 (SD 55.1) minutes per day at T4 (Table 2). Although certain patients increased the time spent on MVPA, there was no significant overall time effect ($F = 1.71$; $p = 0.17$), only a marginal time effect between T1 and T2 (Table 4). The estimated time spent on MVPA at T2 (80.5 + 29.4 = 109.9) was significantly more than at T1 ($T = 2.1$, $p = 0.04$). It can be stated with 95% certainty that the time spent on MVPA at T2 is 1.0-57.9 min more than at T1 (95% CI 1.0-57.9). At T1, 76% of the participants

Table 3 Daily physical activity at T1, T2, T3 and T4 with comparison with the steps-criteria and the ACSM criteria for lifestyle classification

Lifestyle classification[a]	Number of steps/d		T1	T2	T3	T4
	Mean steps/ d (SD)		6326 (2906)	7878 (3756)	7680 (3532)	7562 (3785)
Sedentary	<5000	*n (%)*	8 (32.0%)	6 (25%)	4 (18.2%)	5 (20.9%)
Low-somewhat physically active	5000-10 000	*n (%)*	13 (52.0%)	12 (50%)	13 (59.1%)	13 (54.2%)
Physically active	>10.000	*n (%)*	4 (16.0%)	6 (25%)	5 (22.7%)	6 (25.0%)
Lifestyle classification[b]	**MVPA in min/d**		**T1**	**T2**	**T3**	**T4**
	Mean MVPA (SD)		80.4 (63.6)	110.0 (75.4)	99.1 (61.9)	93.2 (55.1)
Sedentary	<30	*n (%)*	6 (24.0%)	3 (12.5%)	2 (9.1%)	2 (8.3%)
Physically active	>30	*n (%)*	19 (76.0%)	21 (87.5%)	20 (90.1%)	22 (91.7%)

ACSM, American College of Sports Medicine; MVPA, moderate-to-vigorous intensity physical activities.

[a] Lifestyle classification based on the steps-criteria as proposed by Tudor-Locke et al. 2008 (14)

[b] Lifestyle classification based on the ACSM guideline (12, 13)

achieved the recommended level of 30 min MVPA per day, and this increased to 91.7% at T4. Detailed lifestyle classifications at T1, T2, T3 and T4 based on the amount of time spent on MVPA are presented in Table 3.[12, 13]

Table 4 Estimates of fixed effects of time on time spent on MVPA according to linear mixed effect analysis (n = 28)

					95% CI	
	Estimate	**SE**	**T**	**p**	**Lower**	**Upper**
(Intercept)[a]	80.5	12.7	6.3	<.001	55.2	105.9
T2	29.4	14.2	2.1	0.04	1.0	57.9
T3	24.4	13.8	1.8	0.08	-3.0	51.9
T4	16.6	13.3	1.2	0.22	-10.0	43.2

CI, confidence interval; MVPA, moderate-to-vigorous intensity physical activities.

[a] 1.5 months (Intercept), three months (T2), six months (T3), 12 months (T4) after transplantation

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Metabolic characteristics

BMI of the participants significantly increased over time ($F = 12.62$; $p < 0.001$). Compared to T1, BMI was 0.8 kg/m^2 , 1.1 kg/m^2 , and 1.7 kg/m^2 higher at respectively T2, T3 and T4 (Table 5). There was a significant increase in fat percentage over time ($F = 14.63$; $p < 0.001$). Compared to T1, fat percentage was 1.7%, 2.5%, and 3.8% higher at respectively T2, T3, and T4 (Table 6). There was no significant change in fat free mass over time ($F = 0.07$; $p = 0.97$).

Clinical characteristics

There was no significant time effect of renal function as indicated by GFR ($F = 0.17$; $p = 0.92$).

Table 5 Estimates of fixed effects of time on BMI according to linear mixed effect analysis (n = 28)

	Estimate	SE	T	p	95% CI Lower	95% CI Upper
(Intercept)[a]	25.2	0.66	38.27	<.001	23.9	26.6
T2	0.8	0.17	4.73	<.001	0.5	1.2
T3	1.1	0.24	4.62	<.001	0.6	1.6
T4	1.7	0.30	5.78	<.001	1.1	2.3

Abbreviations: BMI, body mass index; CI, confidence interval.

[a] 1.5 months (Intercept), three months (T2), six months (T3), 12 months (T4) after transplantation.

Table 6 Estimates of fixed effects of time on fat percentage according to linear mixed effect analysis (n = 28)

	Estimate	SE	T	p	95% CI Lower	95% CI Upper
(Intercept)[a]	29.7	1.81	16.36	<.001	26.0	33.3
T2	1.7	0.57	3.04	0.003	0.6	2.9
T3	2.5	0.58	4.30	<.001	1.3	3.7
T4	3.8	0.58	6.47	<.001	2.6	4.9

CI, confidence interval

* 1.5 months (Intercept), three months (T2), six months (T3), 12 months (T4) after transplantation.

Discussion

It can be concluded that kidney transplant recipients increase their number of steps per day over time in the first year following transplantation, without being prompted by a specific intervention. However, most patients do not achieve the recommended level of physical activity one year after transplantation. In the first three months after transplantation, the recipients also started to increase the minutes spent on MVPA, but after three months this increase diminished. Although BMI increased, especially due to an increase in fat percentage, there was no significant change in renal function over time.

There was no information about the pre-transplantation physical activity level of the participants in the present study, but other studies indicated that most patients with chronic kidney disease are physically inactive.[17-19] Because physical inactivity is a risk factor for developing cardiovascular disease following transplantation, it is important for kidney transplant recipients to increase physical activity to the recommended levels.[4, 33, 34] Studies with self-reported physical activity reported inconclusive results whether kidney transplant recipients increase physical activity after transplantation.[4, 20] However, self-reported physical activity may be less valid and less sensitive to change compared to accelerometry.[23] The present study, in which physical activity was measured with an accelerometer, demonstrated that kidney transplant recipients become more physically active, especially in the first three months following transplantation. Although it was intuitively expected that younger patients performed better than older patients, this could not be confirmed by *post-hoc* analyses. We hypothesize that the initial increase in physical activity is mostly due to the recovery from surgery. After three months, the increase in physical activity stagnates (number of steps) or even decreases (MVPA). This demonstrates that the majority of patients require additional support to increase their physical activity to the recommended levels and to remain active at the long term.

Kidney transplant recipients are currently recommended to achieve 30 cumulative minutes of MVPA per day.[12, 13] Six wk after transplantation, 76% spent at least 30 min per day at MVPA, and this slightly increased to 91.7% one yr post-transplant. This could lead to the belief, therefore, that most patients are meeting the recommended level of physical activity. However, it should be kept in mind that the recommended 30 min of MVPA should be in addition to routine daily activities and in bouts of minimally ten consecutive minutes.[12, 13] The accelerometer, however, was not able to make a distinction between extra MVPA and routine MVPA and to take into account specific bout lengths of MVPA. This most probably has led to some overestimation of the number of patients who were considered physically active according to the ACSM guideline. Therefore, it is informative to consider another physical activity outcome as a source for data as well. The number of steps per day provides a beneficial impression of physical activity per day, as every step is taken into consideration and not only the steps at a certain intensity. An average of 10 000 steps per day is recommended. [14] Six wk following transplantation, 16% of our participants took an average of 10 000 steps per day and, although this slightly increased to 25% one yr post-transplantation, this demonstrates that the majority did not meet the recommended number of steps. The fact that many recipients are able to accumulate at least 30 min of MVPA per day, but accumulate less than 10 000 steps per day, seems due to compensatory decreases in other daily physical activities with lower intensities.[35] Taken together, many patients are not sufficiently physically active according to the guidelines, which is in line with other studies [4, 9, 22] and comparable to other organ transplant recipients.[36, 37] However, the present study showed that meeting the recommended levels of physical activity is not impossible, as 25% of the participants in the present study took an average of at least 10 000 steps per day.

Although the kidney transplant recipients did not receive structural physical activity advice from their physicians, there was an initial increase in physical activity following transplantation. However, for most patients additional support is necessary to achieve the recommended physical activity levels. Other studies have stressed the importance of health care providers encouraging kidney transplant recipients to become physically active on a regular basis as well.[3-5, 19, 38-41] This is not only necessary during the first year following transplantation, but also for an ongoing period of time as research indicates that health promotion behaviors (such as medication adherence and physical activity) decline with increased post-transplant time.[5] We advise, therefore, physicians to encourage kidney transplant recipients each hospital visit to become more physically active. To optimize physical activity interventions, more knowledge is required about which factors affect physical activity in this population. Literature showed the capacity to perform physical activities may be limited by central, peripheral, and psychological factors. For example, research showed that the exercise capacity of kidney transplant recipients is negatively affected by poor blood pressure control.[42] Other research showed that an impaired exercise capacity may be the result of an underlying muscle defect, including reduced skeletal muscle NA+, K+ -pump activity.[43] Also psychological factors may play a role, as Gordon et al.[22] showed that self-efficacy was associated with physical activity. In addition, we recommend kidney transplant recipients to regularly visit a physical therapist or physical activity counselor for physical activity counseling. This, in combination with nutritional advice of a dietician, could result in synergetic effects which are beneficial for the recipients.

The participants in this study significantly gained weight in the first post-transplantation year, which is mainly attributed to an increase in fat percentage. This common finding in kidney transplant recipients [3, 8, 44, 45] is a worrisome phenomenon as it increases the risk of perioperative complications, metabolic syndrome, cardiovascular disease and mortality.[3, 45, 46] An interactive effect between remaining inactive, unhealthy diet and gaining weight is likely to occur. To reduce the detrimental risks, not only a healthy diet, but also regular physical activity is a promising strategy. Several studies showed the beneficial effects of physical activity on body composition, weight, cardiovascular disease and mortality in kidney transplant recipients. [4, 8, 34]

Physical inactivity and obesity are possible risk factors for loss in renal function.[9, 10, 45] Although the recipients in this study showed no significant changes in renal function during the first year following transplantation, several other studies emphasized the need for kidney transplant recipients to follow health care recommendations (including physical activity and healthy diet) to reduce the risk of loss of kidney function.[5, 22] Other studies have demonstrated that a lack of physical activity and an increase in weight may have negative consequences for kidney function. [9, 10, 45] Gordon et al.[9] demonstrated in a study with 88 recipients that greater physical activity is positively associated with improved kidney function in the first year following transplantation. Another study (n = 2117) showed that not only activities of at least moderate intensity are associated with kidney function but also light intensity and total physical activities.[10]

When interpreting the results of the present study, certain characteristics of the study should be taken into account. The sample size is relatively small, making standard errors and confidence intervals larger, but it was sufficiently large to detect differences in physical activity between different time points. Furthermore, the sample is representative for the general kidney transplant recipient population. Sample size was not sufficiently large for a thorough examination of the effect of several explanatory factors of physical (in)activity. For such an epidemiological type of research question a larger sample size is required. Furthermore, it is recommended for future research to include a pre-transplantation measurement, to assess whether post-transplantation physical activity levels return to pre-transplantation levels. Progress has been made by measuring daily physical activity in a performance-based way with accelerometry when compared to self-report measurements of daily physical activity, but physical activity was monitored for only three weekdays at each measurement. There is no consensus yet on the number of measurement days required to accurately measure daily physical activity.[47] Several studies recommend to measure daily physical activity for 3-7 d to accurately obtain an overall view of actual daily physical activity.[48] Other studies suggest that fewer days of monitoring daily physical activity can be sufficient in older adults due to less variability between days.[49, 50] This is probably also true for (part of) the present sample, therefore and, taking into consideration the availability of the devices, it was decided to monitor daily physical activity for three consecutive weekdays. It should also be taken into account that from the accelerometer data it was not possible to distinguish between routine and additional minutes of MVPA, and which minutes of MVPA were in bouts of at least 10 min. This could have led to an overestimation of recipients achieving the 30 min of MVPA as recommend by the ACSM.[12, 13] Future research should focus on developing a device which can measure steps and physical activities at different intensities in specific populations, but which is also able to make a distinction between extra and routine MVPA, and in 10-min bouts of MPVA. Furthermore, such a device should be easy to use for researchers and participants, with a low participant burden, and be able to be worn continuously for extended periods of time.

In conclusion, although kidney transplant recipients increased physical activity during the first post-transplantation year, the majority does not meet recommended levels of physical activity. In addition to weight gain, this may potentially lead to an increased risk of kidney function loss, cardiovascular disease and mortality. Therefore, it is important to develop strategies for health care providers to support kidney transplant recipients to comply with healthy lifestyle recommendations, including regular physical activity.

Disclosure

No conflicts of interest.

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General discussion

In this thesis, the daily physical activity of patients with a chronic disease such as congenital heart disease (**Chapter 2**), heart disease, diabetes, asthma, breast cancer, arthritis and depression (**Chapter 3**), heart failure (**Chapter 4**), Parkinson's disease (**Chapter 5**), and renal transplant recipients (**Chapter 6**) was examined in order to gain more insight into how physically active patients are and which factors are related to physical activity in patients with a chronic disease.

Daily physical activity in patients with a chronic disease

This thesis demonstrates that there is a large variability in daily physical activity in patients with a chronic disease. Even in patients who identified themselves as sedentary, there is a considerable variation in the sense that some are indeed sedentary, but some are semi-active (1-4 days/week of 30-min activity). Although most chronic patients do not to meet the recommended levels of physical activity, there are certain patients with a (severe) chronic disease who are physically active enough to even meet the recommended levels for *healthy* adults. This illustrates that it is possible for patients with a (severe) chronic disease to meet the physical activity guidelines.[1-3] This provides hope for the possibility that inactive patients can become more physically active in daily life, keeping in mind that even some physical activity is considered better than none.[4-7] It should be noted, however, that there can be a large variability in severity and limitations of diseases. Therefore, it can be questioned whether the current physical activity guidelines are appropriate to apply for all patients with a chronic disease. Based on the findings of this thesis, it is recommended to tailor the current physical activity guidelines to the abilities and needs of patients with different diseases.

Physical activity guidelines

There are a number of features of the current physical activity guidelines which caused confusion when interpreting, advising, and monitoring the compliance to the guideline for patients with a chronic disease. To date, adults (50-64 years) with clinically significant chronic conditions or functional limitations are recommended to comply to the recommendations for healthy adults to the extent that their abilities and conditions allow.[1, 2] There are numerous guidelines and recommendations for healthy adults;[1] one of the leading recommendations originates from the American College of Sports Medicine (ACSM) and the American Heart Association (AHA). To promote or maintain health, the ACSM/AHA recommend adults to accumulate at least 30 minutes of moderate-to-vigorous intensity physical activity (MVPA) at least five days per week.[1, 2]

To comply to the ACSM/AHA guideline, patients should attempt to accumulate at least 30 minutes of MVPA at least at 5 days per week, however, what exactly is moderate-to-vigorous intensity? Although this can be expressed in Metabolic Equivalents of Tasks [METs],[8] it should be

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noted that the intensity level of an activity is relative to an individual's aerobic fitness and capacity. As the physical fitness and capacity of patients can vary tremendously, there will be a difference in activities which can be considered as moderately intensive. For certain patients, a slow walk is moderately intensive while, for others, the walk is only moderately intensive when it is performed at a brisk pace.

Another feature which requires further clarification is that, according to the ACSM/AHA physical activity guideline, the 30 minutes of MVPA should be conducted in bouts of ten consecutive minutes at a minimum. However, as shown in **Chapter 5**, performing moderate-intensity activity for a minimum of 10 consecutive minutes can be problematic for certain patients. Although approximately 50% of the patients with Parkinson's disease performed 30 minutes of activity per day, only 18% performed 30 minutes of activity per day in multiple bouts of minimally 10 minutes. This suggests that most patients are not capable of performing moderate intensity physical activity for 10 consecutive minutes, but it is unclear whether these 10-minute bouts (which are currently recommended) are actually necessary to produce health effects in patients with a chronic disease.

The third ambiguous feature is that the 30 minutes of MVPA should be *in addition* to the daily routine activities (e.g., self-care, cooking, shopping).[1, 2] It should be noted that it is often difficult to determine which activities are routine or which are additional activities. Therefore, I would argue to consider another physical activity outcome as well, such as the average number of steps per day.

A popular recommendation is that adults should take an average of 10,000 steps per day to maintain health.[3] Research indicated that this '10,000 steps recommendation' is fairly equivalent to the ACSM/AHA recommendation (30 min MVPA in addition to routine activities).[9-11] Thirty minutes of walking results in approximately 3,000-4,000 steps; daily routine activities result in approximately 6,000-7,000 steps.[9, 10] Thus, when an individual is active for 30 minutes in addition to the daily routine activities, a total number of 9,000-11,000 steps is likely to be achieved.

The fourth confusing feature, i.e., the addition of "meeting the recommended level *as much as their abilities and conditions allow"*, applies for both guidelines (ACSM/AHA and 10.000 steps). Although this appears reasonable, it creates difficulties in interpreting, advising, and monitoring compliance to this guideline for patients with a chronic disease.

Taken together, although many patients are not meeting physical activity recommendations, it is questionable whether the current guidelines are appropriate to classify them as physically inactive. Together with the large variability in physical activity and in severity and limitations of diseases, this calls for more concrete, tailored, and disease specific physical activity guidelines.

Methods of measuring physical activity

In order to monitor compliance to physical activity guidelines, it is important to measure daily physical activity with a reliable and valid method. An accurate measure of daily physical activity should be able to assess the intensity, frequency, duration, type of activity, and total amount of physical activity. There are many different ways to measure physical activity including subjective measures (e.g., diary, interviews, and questionnaires) and objective measures (e.g., indirect calorimetry, doubly labelled water, pedometers, accelerometers, and heart rate monitors). It is difficult to compare with other studies because there are many differences in which method is used to measure physical activity, which physical activity outcome is used, and which (pre) processing rules are followed to analyse the physical activity data.

Subjective measures such as questionnaires are often utilized because they are easy to administer, inexpensive, applicable on a large scale, and can be employed to classify respondents into active versus inactive.[12] Therefore, physical activity of the participants of the Australian Study on Women's Health was measured with questionnaires (**Chapter 3**). Although the self-reported physical activity data can provide a distinct indication about levels of physical activity and, more importantly, change in physical activity, it should be noted that subjective measures of physical activity have certain disadvantages as well. They are prone for validity and reliability deficiencies and are inclined to overestimate physical activity.[12, 12-18] Measurement error can be large, because responses to questionnaires are influenced by perception, cultural factors, social desirability, and the memory of the respondent.[13] Lifestyle physical activities are especially difficult to measure with a questionnaire because these are extensively habitual and require only minimal conscious processing.[19] Therefore, physical activity is currently often measured by performance-based methods such as accelerometry. The use of accelerometry is increasing due in part to the increasing availability of small and inexpensive sensors.

Accelerometers are small, easy to use, affordable, widely applicable, and generally accurate, valid, and reliable.[14, 20-23] These instruments register actual daily physical activity in a performance based manner and can, therefore, provide accurate and detailed information regarding the pattern, diversity, duration, and intensity of daily physical activity throughout the day and about compliance to daily physical activity guidelines. Such devices are less expensive, less burdening and less expensive compared to indirect calorimetry and double labeled water techniques (often used as the golden standard)[14, 24-26] as well as more objective and less sensitive for socially desirable answers compared to self-reported measures of physical activity.

There are numerous different accelerometers, however, there is no accelerometer which has yet been extensively proven to be the golden standard. From the numerous different devices, researchers can select the most appropriate device by taking several factors into consideration, e.g., characteristics of the participants, psychometric properties, feasibility, goal of measuring physical activity, and the research question and study design.[12, 20] To measure daily physical activity in patients with heart failure (**Chapter 4**) and in renal transplant recipients (**Chapter 6**), the Sensewear Pro3 Armband (BodyMedia, Inc., Pittsburgh, PA) was selected. To measure the physical activity of patients diagnosed with Parkinson's disease (**Chapter 5**), the choice was made to use the Direct Life (TracmorD, Philips New Wellness Solutions, Lifestyle Incubator, the Netherlands). The fact that researchers can select a device that is the most sufficient for their preferences is a positive development but has also a negative aspect. The various accelerometers have different outcome measures, which makes it difficult to compare between studies.[27] For example, certain studies use activity counts as outcome measure,[28, 29] others use energy expenditure,[30] peak daily physical activity,[31] steps,[30, 32] or the amount of time spent performing moderate-to-vigorous intensity physical activities.[30, 32]

It is not only difficult to compare between studies using different outcome measures but also comparing between studies with the same outcome measure appears to be difficult. Accelerometers apply varying techniques and algorithms to measure and calculate the same outcome measure, which can lead to different results. Furthermore, there is a lack of consensus about processing accelerometer data. For example, there is no consensus yet regarding the number of days that should be monitored for an accurate measurement, the minimal wearing time per day, or the allowable interruption period, etc.[33, 34] Different methods for processing the same data can result in different conclusions with regard to compliance to physical activity guidelines.[33-35]

Ongoing research is necessary to keep track of the best way to measure physical activity and to develop guidelines for standardization of processing accelerometer data. Based on the experiences in this thesis, it is recommended to follow best practice recommendations as much as possible when processing accelerometer data.[33-38] Furthermore, it is important to report the decisions regarding (pre)processing accelerometer data as accurately as possible including choice of device, minimum daily wear time, minimal wear time required for a valid day, number of days, bout-length, cut points, imputation, etc.[33-36, 38] Consequently, it becomes possible to better compare physical activity data from various studies using different objective measures and to draw firm conclusions about compliance to physical activity guidelines.

Determinants of physical activity

Physical activity behaviour is a complex behaviour and still not fully understood, especially in patients with a chronic disease. Although, intuitively, it is expected that a disease has large impact on the level of physical activity of patients, this thesis suggests that physical activity is influenced by generic factors rather than by the disease.

As shown in **Chapter 3**, there is no effect of being diagnosed with a chronic disease on the level of physical activity. Some newly diagnosed patients decreased their physical activity while other patients increased their physical activity. The majority, however, remained at the same physical activity level after being diagnosed with a chronic disease as that before the diagnosis. This pattern of change is relatively stable across years and not specifically affected by the diagnosis of a disease. The severity of the disease is often associated with physical activity,[39-41] as also shown in **Chapter 4**. Patients with a more severe disease are more likely to have low levels of physical activity. However, this is not true for every patient since some patients with a severe disease are physically active enough to meet the recommended levels for healthy adults. For example, in this thesis, it was demonstrated that even some patients with severe heart failure (NYHA III) met the level of physical activity which is also recommended for healthy adults (**Chapter 4**). Certain patients with congenital heart disease also met the recommended levels of physical activity (**Chapter 2**). Some self-identified sedentary patients with Parkinson's disease are actually meeting the recommended levels of physical activity which also apply for healthy adults (**Chapter 5**). Additionally, some patients are already meeting physical activity guidelines only 6 weeks after receiving a donor kidney (**Chapter 6**).

This thesis demonstrates that the level of physical activity in patients with a chronic disease is only partially influenced by the disease (severity), however, possibly more by other factors such as the level of education, BMI, and psychological factors such as self-efficacy. Perhaps these factors determine to which degree patients appeal to their physical capacity –which is influenced by their disease- to be physically active.[42]

Furthermore, since disease specific, psychological, and demographic factors collectively do not completely explain physical activity behaviour, it is recommended that physical activity researchers combine their knowledge with other scientific perspectives to solve the puzzle of physical activity behaviour. An example is the environmental health perspective. Recently, there is an increased interest in the relationship between physical activity and the built environment.[43-49] For example, research showed that the presence of walking paths in the direct neighbourhood is positively related to physical activity, whereas perceived unsafety is negatively related to physical activity.[45]

Overall, physical activity behaviour of patients is very complex. Further research is required in order to assess which factors determine physical activity, but this thesis showed that the disease itself is probably not the most important factor. Instead, I hypothesize that the degree in which patients appeal to their physical capacity in order to be physically active is determined by psychological factors such as self-efficacy and motivation, as well as by environmental factors such as the quality of the neighbourhood and physically active-friendly-infrastructures.

Understanding the factors that influence physical activity behaviour in patients will have consequences for the strategy we should be using to enhance physical activity of inactive patients. Do we need to use cognitive therapy to increase self-efficacy? Or do we need to ensure that our environment is inviting us to become more physically active? Or maybe both? Do we require a different strategy for highly educated people than for low educated people? In any event, it is questionable whether it is possible at all to change physical activity behaviour in patients.

Can physical activity be increased in patients with a chronic disease?

This thesis has demonstrated that the variation in daily physical activity is large in patients with a chronic disease, which suggests that a more active lifestyle for more patients is within the possibilities. However, **Chapter 3** showed that, although certain changes in physical activity are possible as either an increase or a decrease, the majority of people remain at the same level of physical activity for years. Moreover, **Chapter 6** showed that, even when the disease is more or less 'cured' (renal transplantation) and the former patients could, theoretically, be physically active enough to comply to guidelines for healthy adults, it is not a guarantee that they will increase their physical activity to satisfactory levels. Many interventions are successful in increasing physical activity for a certain period of time,[50-52] however, the long-term results show that it is often difficult to continue complying to the new physical activity routine.[53, 54] Physical activity seems to be a reasonably stable behaviour across years.[55]

Altogether this suggests that people are 'programmed' at a certain physical activity level. It could be interpreted as a physical activity thermostat which is set at a certain level. This can be an innate determined set point (nature) but can also be determined by personal experiences in life (nurture) or by a combination of both. For example, if both parents are used to a physically active lifestyle, it is likely that this will be passed to their offspring either by genes or by the way they raise their children. Although fluctuations around the pre-set level are possible either due to an intervention, certain life-events, or just life in general, people are inclined to their pre-set level of physical activity. Other researchers hypothesized something similar, i.e., the ActivityStat hypothesis.[56] When physical activity is increased or decreased in one domain, this hypothesis suggests that people will compensate in another domain in order to maintain a stable total level of physical activity. Further research should confirm these hypotheses; however, if they are true, it signifies that it is even more difficult to change physical activity as it has been assumed until now.

Recent developments in strategies to increase physical activity

Although there are some promising strategies, to date, the holy grail of strategies to increase physical activity has not yet been discovered. However, new, surprising, original, and promising ideas *are emerging*.

For example, there is an increasing interest in 'quantified self' as illustrated by the growing Quantified Self Community[57] and the launch of the Quantified Self Institute.[58] An increasing number of people would like to measure a certain aspect about themselves such as physical activity, stress, mood, or sleep. Their goal is to learn from their data (self-knowledge through numbers) to make healthier choices in life. With regard to physical activity, many different activity trackers have been developed and available for individual users, e.g. Fitbit One, Jawbone Up, Misfit Shine, etc. Each device can provide insight for the user into his/her physical activity behaviour. However, from earlier theories and studies, it is known that being aware of something is not enough incentive to establish long-lasting changes in behaviour.[19, 59] However, specific features of these devices such as direct feedback, gamification, and the ability of peer comparison via social media should make an active lifestyle more fun which is, in my opinion, an important factor to succeed in obtaining, having, and keeping an active lifestyle. To date, only the 'early adopters' are engaged in the world of Quantified Self. People who are not interested in physical activity are also not interested in monitoring their activity with an activity tracker and will not be sensitive for the feedback of such devices to change their behaviour. However, perhaps inactive persons are also willing to track their physical activity when activity trackers become common practice in health care, and the expense is reimbursed by health insurance companies. The same is true for self-tracking of other health behaviours such as eating habits, stress, and sleep. Eventually, the popularity of quantifying certain aspects of themselves will extend to the early majority, the late majority, and the laggers.

Another recent development is the acknowledgement of the risks of a sedentary lifestyle, independent of the risks of an inactive lifestyle.[60-63] Sedentary behavior and physical activity are not two sides of the same coin, but are two different constructs with different determinants and different effects on health.[62, 64] Too little physical activity is something different then too much sedentary behavior.[62, 65-67] Sedentary behavior (from the Latin sedere – to sit) is defined as activities with a low energy expenditure ($\leq$1.5 METs; multiples of the basal metabolic rate) which involves sitting or reclining (excluding sleep).[60, 62, 66, 67] In that respect, 'sedentary behavior' refers to sitting/lying with low energy expenditure instead of the absence of MVPA.[61, 66, 67]

Research showed that sedentary behavior is a health risk factor independent of the amount of physical activity.[60-63] Otherwise stated, it is possible for someone to meet all physical activity recommendations (30 min/day MPVA), however, due to prolonged sitting during the remainder of the day, still have significant health risks. This is also known as the Active Couch Potato phenomenon.[62, 68] It is suggested that replacing sedentary activities with light-intensity physical activities may reduce the detrimental effects of prolonged sitting independent of the time spent in MPVA.[61, 62, 69-72]

Time spent in MVPA is only a small proportion of the waking hours, and research suggests that increasing time spent in MVPA cannot fully compensate the increased health risks of long periods of sitting.[69, 73, 74] Furthermore, people often feel that they do not have time to do more MPVA. Patients may also encounter other barriers to engaging in MVPA such as physical or psychological limitations. Furthermore, as shown in **Chapter 2**, many patients are not willing to perform exercise. Therefore, to stimulate patients to adopt an active lifestyle, it may be worthwhile to not only aim at increasing physical activity but also at decreasing sedentary behaviour.

Advice: take your responsibility

Patients should be encouraged to increase physical activity, limit total sitting time, and break up prolonged sitting more often, thereby stressing the importance of listening to their own body.[60, 75, 76] Unfortunately, as shown in this thesis, despite the well-known benefits of physical activity for patients, many patients are not regularly physically active. To date, it is not always routine clinical practice to provide physical activity advice and encourage patients to become more physically active. For example, 39% of the patients with heart failure in the study described in **Chapter 4** reported that they had not received physical activity advice from their cardiologist. Another study reported that 37% of patients with congenital heart disease did not receive physical activity advice from their cardiologist.[51]

This is understandable since physicians are not trained in prevention and, therefore, possess only minimal knowledge and skills regarding physical activity and counselling as well as often having limited time per consult.[77, 78] However, due to the clear benefits of physical activity in preventing and treating chronic diseases, physicians need to feel more responsibility for prescribing physical activity to their patients just as they prescribe medications.[79, 80] Research showed that physicians can be successful in increasing physical activity in patients,[81] although there appears to be more to it than just prescribing physical activity.[79] Unfortunately, to date, the education on preventive medicine is considered inadequate, and there is yet no profession with prevention and management of chronic disease as a core business.[77] However, in order to prevent and treat chronic diseases, it is urgently necessary for physicians to learn more about their patient's physical activity, its determinants, and about the best strategies to ensure positive and long-lasting changes in physical activity.

In conclusion

Based on this thesis, it can be concluded that, although there is a large variability in physical activity between patients, many patients are not meeting the recommended levels of physical activity. However, the current guidelines must be more concrete, tailored, and disease specific in order to exactly evaluate the amount of physical activity in patients. Furthermore, to measure physical activity, it is recommended to use objective methods and to follow literature based guidelines regarding (pre)processing accelerometer data as much as possible. This will afford researchers and health care providers an opportunity to compare physical activity in patients between different studies. The level of physical activity in patients can be determined by numerous different factors, but this thesis suggests that the disease itself is probably not the most important factor. It is hypothesized that the degree in which patients appeal to their physical capacity to be physically active is determined by psychological and environmental factors. Health care providers should take responsibility for stimulating inactive patients to become more physically active and less sedentary in daily life, thereby keeping an open mind for new trends and collaborate with other sciences, such as environmental health, sensor technology, and the Quantified Self Community.

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Summary

In **Chapter 1**, it is described that regular physical activity is not only important for healthy persons but also for persons who already have a chronic disease. It can decrease the progression or complications of the disease and can improve social well-being and the quality of life. Not only exercise has beneficial health effects but also daily physical activity such as walking, cycling, gardening, etc. To date, little is known about daily physical activity in patients with a chronic disease.

This thesis examined the physical activity behaviour of patients with a chronic disease including congenital heart disease (**Chapter 2**), heart disease, diabetes, asthma, breast cancer, arthritis, and depression (**Chapter 3**), heart failure (**Chapter 4**), Parkinson's disease (**Chapter 5**), and renal transplant recipients (**Chapter 6**).

It has only been recently recognized that patients with congenital heart disease should be encouraged to be physically active, including participation in exercise training and sports. Therefore, an individualised exercise program was developed for grown-ups with congenital heart disease. **Chapter 2** describes a cross-sectional study in which the willingness of 116 grown-ups with congenital heart disease to participate in that exercise program was examined. Results demonstrated that 59% of the respondents were willing to participate whereby their perceived physical fitness and motivation for physical activity in general were important predicting factors. The majority of patients who were not willing to participate were already satisfied with their physical fitness. Unfortunately, patients with congenital heart disease tend to overestimate their physical capacity. Furthermore, most patients were physically inactive as only 17% of the respondents met the physical activity recommendation of at least 30 minutes per day of moderate to vigorous physical activity for most days of the week.

For newly diagnosed patients, it is important to become regularly physically active in order to successfully manage their chronic disease. **Chapter 3** describes a longitudinal study in which the changes in the level of physical activity in 4840 women were examined after being diagnosed with a chronic disease such as heart disease, diabetes, asthma, breast cancer, arthritis, and depression. Results indicated that the majority did not increase their level of physical activity. The proportions of women who decreased, increased, and who remained at the same level of physical activity were relatively stable across years before and after diagnosis, thus there was no effect of diagnosis of a chronic disease. Other factors such as the level of education, body mass index, and smoking status had a significant effect on the physical activity level. Women at an older age, higher level of education, a lower body mass index, less depressive symptoms, and who ceased smoking have lower odds of low levels of physical activity.

For heart failure patients, physical activity is the only non-pharmacological therapy that is proven to be effective in reducing morbidity. **Chapter 4** focused on performance-based daily physical activity and related factors in heart failure patients. Results demonstrated that 44% were active for less than 30 minutes per day, and 85% took less than 10 000 steps per day. The variance in daily physical activity was considerable; however, approximately half of the patients had a sedentary lifestyle. More severe heart failure, as indicated by the New York Heart Association classification, and lower self-efficacy were associated with less daily physical activity.

Patients with a chronic disease have often only low levels of physical activity, however, there is also a large variability in physical activity. **Chapter 5** describes a study in which performance-based daily physical activity of patients with Parkinson's disease who had identified themselves as sedentary was examined. Results demonstrated that over 98% of the day was spent on sedentary-to-light-intensity activities, and most self-identified sedentary patients were indeed sedentary. However, the variance in daily physical activity between these patients was considerable, as also illustrated by the finding that 17% of the participants were meeting the recommended levels of physical activity at least one day per week. Higher age, being female, and lower physical capacity were the most important determinants of reduced daily physical activity.

When the disease is cured, for example, in patients with kidney disease after receiving a kidney transplant, there are generally no restrictions for performing physical activities. The study in **Chapter 6** examined the changes in daily physical activity in 28 adult kidney transplant recipients over the first 12 months following transplantation by measuring daily physical activity with an accelerometer at six weeks, three months, six months, and 12 months following transplantation. Although the recipients increased physical activity as indicated by the number of steps per day, the majority did not meet the recommended levels of physical activity after one year. This, in addition to the increased body mass index and fat percentage, may result in negative health consequences.

In **Chapter 7**, the primary findings of this thesis are discussed. Based on this thesis, it can be concluded that many patients are not meeting the recommended levels of physical activity, and that there is a large variability in physical activity between patients. It is suggested that the current guidelines must be more concrete, tailored, and disease specific in order to exactly evaluate the amount of physical activity in patients. Furthermore, to measure physical activity, it is recommended to use objective methods and to follow literature based guidelines regarding (pre)processing accelerometer data as much as possible. This will allow researchers and health care providers to compare the physical activity of patients between different studies. The level of physical activity of patients can be determined by numerous different factors, but this thesis suggests that the disease itself is probably not the most important factor. It is hypothesized that the degree in which patients appeal to their physical capacity to be physically active is determined by psychological and environmental factors. Health care providers should take responsibility for stimulating inactive patients to become more physically active and less sedentary in daily life, thereby keeping an open mind for new trends and collaborating with other sciences such as environmental health, sensor technology, and the Quantified Self Community.

Samenvatting

In **Hoofdstuk 1** wordt op basis van de bestaande literatuur het belang van fysieke activiteit in het dagelijkse leven voor mensen met een chronische aandoening beschreven. Dagelijks bewegen kan de progressie en complicaties van ziekten verminderen. Daarnaast kan fysieke activiteit het sociaal welbevinden en de kwaliteit van leven verbeteren. Net als sportactiviteiten hebben dagelijkse fysieke activiteiten zoals wandelen, fietsen en tuinieren een positief effect op de gezondheid. Tot op heden is er nog weinig bekend over de dagelijkse fysieke activiteit van patiënten met een chronische aandoening.

In dit proefschrift staat onderzoek naar het beweeggedrag van verschillende groepen patiënten met een chronische aandoening zoals aangeboren hartafwijkingen (**Hoofdstuk 2**), hartziekte, diabetes, astma, borstkanker, artritis, en depressie (**Hoofdstuk 3**), hartfalen (**Hoofdstuk 4**), de ziekte van Parkinson (**Hoofdstuk 5**), en patiënten na een niertransplantatie (**Hoofdstuk 6**), centraal.

Het wordt pas sinds kort erkend dat het van belang is dat patiënten met een aangeboren hartafwijking fysiek actief zijn. Hierbij zijn niet alleen dagelijkse fysieke activiteiten belangrijk, maar ook sportactiviteiten. Ten behoeve van deze inzichten is er een geïndividualiseerd sportprogramma ontwikkeld voor volwassenen met een aangeboren hartafwijking. In **Hoofdstuk 2** van dit proefschrift wordt een cross-sectionele studie beschreven waarin onderzoek is gedaan naar de bereidheid van 116 volwassenen met een aangeboren hartafwijking om mee te doen aan het sportprogramma. Van de respondenten bleek 59% bereid hieraan mee te doen. De door de respondenten ervaren fysieke fitheid en motivatie om te bewegen waren de belangrijkste voorspellende factoren voor hun bereidheid om mee te doen aan het sportprogramma. De meeste patiënten die niet mee wilden doen aan het sportprogramma gaven aan al tevreden te zijn met hun fysieke fitheid. Helaas hebben patiënten met een aangeboren hartafwijking de neiging om hun fysieke capaciteiten te overschatten. De meeste patiënten in dit onderzoek waren fysiek inactief; slechts 17% van de respondenten haalde de aanbevolen hoeveelheid fysieke activiteit (30 min per dag matig intensief bewegen op de meeste dagen van de week).

Voor patiënten die gediagnosticeerd zijn met een chronische ziekte is het belangrijk om regelmatig te bewegen. **Hoofdstuk 3** beschrijft een longitudinale studie waarin onderzocht is hoe het beweeggedrag van 4840 vrouwen verandert na de diagnose met een chronische ziekte (hartziekte, diabetes, astma, borstkanker, artritis en depressie). Tussen 1998 en 2010 hebben deelnemers elke 3 jaar een vragenlijst ingevuld over hun beweeggedrag, leefstijl, diagnose en symptomen van ziekten. Analyses over deze vijf meetmomenten toonden aan dat de meeste vrouwen na de diagnose niet méér zijn gaan bewegen dan dat ze voor diagnose deden. De percentages vrouwen die minder zijn gaan bewegen, méér zijn gaan bewegen en evenveel zijn blijven bewegen, waren ongeveer gelijk in de jaren vóór en na diagnose. De diagnose van een chronische ziekte bleek dan ook geen effect te hebben op het niveau van fysieke activiteit. Factoren, zoals opleidingsniveau, body mass index (BMI), en rookgedrag hadden wel een significant effect op het fysieke activiteitenniveau. Vrouwen die ouder en hoger opgeleid waren, een lagere BMI en minder depressieve symptomen hadden en die gestopt waren met roken, hadden minder kans op een lager fysieke activiteitenniveau.

Voor patiënten met hartfalen is fysieke activiteit de enige niet-farmaceutische behandeling die het beloop van het ziektebeeld kan beïnvloeden. **Hoofdstuk 4** beschrijft een onderzoek naar objectief gemeten dagelijkse fysieke activiteit en daaraan gerelateerde factoren, van patiënten met hartfalen. Resultaten hebben aangetoond dat 44% van de patiënten minder dan 30 minuten per dag fysiek actief waren en dat 85% minder dan 10.000 stappen per dag zetten. Ongeveer de helft van de patiënten haalde de aanbevolen hoeveelheid fysieke activiteit niet, maar er was een aanzienlijke variantie in de hoeveelheid dagelijkse fysieke activiteit. Deze variantie werd voornamelijk bepaald door de ernst van de ziekte en eigen-effectiviteit (self-efficacy); ernstiger hartfalen en minder eigen-effectiviteit waren geassocieerd met minder dagelijkse fysieke activiteit. Hiermee zal dus rekening gehouden moet worden bij het stimuleren van fysieke activiteit bij patiënten met hartfalen, bijvoorbeeld door te focussen op het vergroten van eigen-effectiviteit.

Ook al is er een grote variatie tussen patiënten, veel patiënten met een chronische ziekte bewegen te weinig. **Hoofdstuk 5** beschrijft een onderzoek naar dagelijkse fysieke activiteit van patiënten met de ziekte van Parkinson die zichzelf als sedentair beschouwen. Dagelijkse fysieke activiteit was gemeten met een accelerometer op 7 achtereenvolgende dagen. Uit de resultaten bleek dat meer dan 98% van de dag werd besteed aan sedentair tot licht intensieve activiteiten. De meeste patiënten hadden hun eigen beweeggedrag goed ingeschat, aangezien de objectieve metingen bevestigden dat deze patiënten sedentair waren. Er was echter ook een grote variatie in dagelijkse fysieke activiteit tussen deze patiënten. Dit bleek onder andere uit het feit dat 17% van de patiënten zelfs de aanbevolen hoeveelheid fysieke activiteit haalt, op tenminste 1 dag per week. De belangrijkste determinanten van verminderde dagelijkse fysieke activiteit waren: een hogere leeftijd hebben, vrouw zijn en een verminderde fysieke capaciteit.

Wanneer een patiënt genezen is van een ziekte, zoals bijvoorbeeld het geval is als nierpatiënten een donornier hebben ontvangen, zijn er in principe geen beperkingen meer voor fysieke activiteiten. In **Hoofdstuk 6** zijn de veranderingen in de dagelijkse fysieke activiteit van 28 volwassen niertransplantatie patiënten in de eerste 12 maanden na transplantatie onderzocht. Daarvoor werd de dagelijkse fysieke activiteit van deze patiënten met accelerometers op vier meetmomenten gemeten: zes weken, drie maanden, zes maanden en 12 maanden na de transplantatie. Ook al gingen de getransplanteerde patiënten meer bewegen (meer stappen per dag), na een jaar haalden de meeste patiënten nog steeds niet de aanbevolen hoeveelheid fysieke activiteit. Dit, samen met de verhoogde BMI en vetpercentage, kan resulteren in nadelige gezondheidseffecten. Deze bevindingen illustreren het belang om een strategie te ontwikkelen die niertransplantatie patiënten kan ondersteunen om meer te gaan bewegen.

In **Hoofdstuk 7** worden de belangrijkste bevindingen van dit proefschrift besproken. Op basis van dit proefschrift kan er worden geconcludeerd dat veel patiënten niet de aanbevolen hoeveelheid fysieke activiteit halen. Er bestaat echter wel een grote variatie tussen de patiënten met betrekking tot de hoeveelheid fysieke activiteit. Om het beweeggedrag van patiënten beter te kunnen beoordelen en op waarde te kunnen schatten, zullen de huidige beweegrichtlijnen concreter, op maat gemaakt, en ziekte specifiek moeten zijn. Daarnaast wordt aangeraden om objectieve methodes te gebruiken om fysieke activiteit te meten. Om vervolgens deze data te bewerken en analyseren zouden de richtlijnen uit de literatuur zoveel mogelijk gevolgd moeten worden. Hierdoor wordt het voor onderzoekers en zorgverleners mogelijk om de fysieke activiteit van patiënten in verschillende studies met elkaar te vergelijken. Alhoewel het fysieke activiteitenniveau van patiënten door verschillende factoren beïnvloed kan worden, toont dit proefschrift aan dat de ziekte zelf waarschijnlijk niet de belangrijkste factor is. Er wordt verondersteld, dat de mate waarin patiënten een beroep doen op hun fysieke capaciteit om fysiek actief te zijn, bepaald wordt door psychologische- en omgevingsfactoren. Zorgverleners zouden meer hun verantwoordelijkheid moeten nemen om inactieve patiënten te stimuleren fysiek actiever en minder sedentair te zijn in het dagelijkse leven. Daarbij is het van belang om open te staan voor nieuwe trends en samen te werken met andere vakgebieden zoals Environmental Health, sensor technologie, en de Quantified Self Community.

About the author | Over de auteur

About the author

Manon Louise Dontje was born on January 20th, 1985 in Hoorn, The Netherlands. She completed her pre-university education in 2003. In 2008 she received her master's degree in Human Movement Sciences at the University of Groningen. Subsequently, she graduated from the international top research master in Clinical and Psychosocial Epidemiology at the University of Groningen, earning her second master's degree in 2010. In the same year she started her PhD research and training program at Hanze University of Applied Sciences (professorship in Health Care and Nursing) and University Medical Center Groningen (department of Epidemiology) in Groningen, the Netherlands. During her PhD research and training program she was a member of the Graduate School for Health Research (SHARE) as well as the knowledge center Care Rehabilitation Education & Sport (CaRES), which enabled her to follow different courses to further develop her research skills.

Manon is currently working part-time at CBO Groningen (Center for Physical Activity and Research). Her work involves exercise counselling, administering fitness tests, implementing and executing multiple projects to encourage inactive people to be more physically active, and scientific research focused on physical activity and sedentary behavior. In her spare time Manon is member of the Scientific Advisory Council of Horses and Humans Research Foundation to contribute to research that examines the effect of equine-assisted activities and therapies on health and well-being of humans. In February 2014 Manon started working as temporary Program manager of the Quantified Self Institute in Groningen. Manon is currently pursuing a postdoctoral career in physical activity and sedentary behavior.

Over de auteur

Manon Louise Dontje werd geboren op 20 januari 1985 te Hoorn en is opgegroeid in het Drentse dorpje Rolde. Aan het Dr. Nassau College Quintus te Assen behaalde zij in 2003 haar VWO diploma. Daarna begon zij aan de opleiding Bewegingswetenschappen aan de Rijksuniversiteit Groningen. Hier behaalde zij in 2007 haar bachelor's degree en in 2008 haar master's degree. Aansluitend werd Manon toegelaten tot de internationale top-onderzoeksmaster Klinische en Psychosociale Epidemiologie aan de Rijksuniversiteit Groningen, welke ze in 2010 heeft afgerond. Tijdens deze masteropleiding trad ze in dienst van het lectoraat Transparante Zorgverlening van de Hanzehogeschool Groningen. Dit mondde uit in een promotietraject, met een gedeelde aanstelling bij afdeling Epidemiologie van het Universitair Medisch Centrum Groningen. Haar promotieonderzoek en –opleiding werd ondergebracht bij de Graduate School for Health Research (SHARE) en bij het kenniscentrum Care Rehabilitation Education & Sport (CaRES). Hier heeft ze verschillende cursussen gevolgd waarmee ze zich breed heeft kunnen ontwikkelen op onderzoeksgebied. Tegenwoordig is Manon werkzaam bij het Centrum voor Beweging en Onderzoek (CBO) te Groningen. Sinds 2003 werkt ze hier als Exercise counselor, fitheidstestleider en is ze betrokken bij de implementatie van verschillende bewegingsstimuleringsprogramma's en wetenschappelijk onderzoek. Binnen dit onderzoek ligt de focus voornamelijk op het meten en beïnvloeden van fysieke activiteit en sedentair gedrag. Daarnaast maakt ze zich sterk voor wetenschappelijk onderzoek naar de effecten van paardentherapie op de gezondheid en het welzijn van mensen door zitting te hebben in de Scientific Advisory Council van de Horses and Humans Research Foundation. Vanaf februari 2014 is Manon aangesteld als tijdelijk programmaleider van het Quantified Self Institute te Groningen.

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